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# **South Asian service users and emotional distress: Experiences of help-seeking and service provision**

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A thesis submitted in partial fulfilment of the requirements for the degree of  
Doctor of Clinical Psychology

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## Table of Contents

Chapter Contents .....	ii
List of Tables and Figures.....	v
List of Abbreviations and Symbols.....	vi
List of Appendices .....	vii
Acknowledgements .....	viii
Declaration.....	ix
Summary .....	x

## CHAPTER 1 – LITERATURE REVIEW

### Access to mental health services: a systematic review and meta-ethnography of the experiences of South Asian service users in the UK

1.1	Abstract.....	2
1.2	Introduction .....	3
1.2.1	Political and health context.....	3
1.2.2	Mental health of South Asian communities .....	4
1.2.3	Help-seeking and access to mental health services .....	5
1.2.4	Rationale for the current research.....	7
1.2.5	Aims and objectives.....	8
1.3	Method .....	9
1.3.1	Systematic literature search.....	9
1.3.1.1	Search strategy.....	9
1.3.1.2	Search terms.....	10
1.3.1.3	Inclusion and exclusion criteria .....	11
1.3.1.4	Search outcome .....	12
1.3.2	Quality appraisal .....	15
1.3.3	Characteristics of the literature .....	16
1.3.4	Analytic review strategy.....	27
1.4	Findings .....	29
1.4.1	Theme 1: Distanced from services .....	32
1.4.1.1	Concept 1: <i>Outside of awareness</i> .....	32
1.4.1.2	Concept 2: <i>Outside of cultural norms</i> .....	33
1.4.2	Theme 2: Dilemma of trust .....	34
1.4.2.1	Concept 1: <i>Cannot trust non-Asian professionals</i> .....	34
1.4.2.2	Concept 2: <i>Cannot trust Asian professionals</i> .....	35
1.4.3	Theme 3: Threat to cultural identity .....	37
1.4.3.1	Concept 1: <i>Lack of cultural sensitivity</i> .....	37
1.4.3.2	Concept 2: <i>Lack of collaborative care</i> .....	39
1.5	Discussion.....	41
1.5.1	Implications for policy and clinical practice .....	45
1.5.2	Strengths and limitations of the review .....	47
1.5.3	Recommendations for future research.....	48
1.6	Conclusion .....	49
1.7	References.....	50

## CHAPTER 2 – EMPIRICAL PAPER

### Exploring the lived experiences of South Asian women with medically unexplained symptoms: an interpretative phenomenological analysis

2.1	Abstract.....	58
2.2	Introduction .....	59
2.2.1	Medically unexplained symptoms in context.....	59
2.2.2	Somatisation and cultural idioms of distress.....	60
2.2.3	The experiences and views of South Asian service users with MUS .....	63
2.2.4	Rationale for the current research.....	64
2.3	Method .....	66
2.3.1	Research Design.....	66
2.3.2	Participants .....	67
2.3.2.1	Recruitment .....	67
2.3.2.2	Inclusion and Exclusion Criteria .....	67
2.3.2.3	Sample Characteristics.....	70
2.3.3	Research Procedure .....	73
2.3.3.1	Materials .....	73
2.3.3.2	Interview Procedure .....	74
2.3.3.3	Ethical Considerations.....	74
2.3.4	Data Analysis.....	75
2.3.4.1	Validity.....	77
2.3.4.2	Reflexivity.....	77
2.4	Findings .....	79
2.4.1	Super-ordinate theme 1: Multiple assaults on the self.....	81
2.4.1.1	Sub-ordinate theme 1: <i>Fighting to survive through trauma</i> .....	81
2.4.1.2	Sub-ordinate theme 2: <i>Powerless against the pain</i> .....	83
2.4.2	Super-ordinate theme 2: Suffering in silence.....	84
2.4.2.1	Sub-ordinate theme 1: <i>Shame, stigma, and isolation</i> .....	84
2.4.2.2	Sub-ordinate theme 2: <i>Dismissed and alienated by professionals</i> .....	85
2.4.3	Super-ordinate theme 3: Reconstructing the self .....	87
2.4.3.1	Sub-ordinate theme 1: <i>Struggling to find explanations</i> .....	87
2.4.3.2	Sub-ordinate theme 2: <i>Navigating resilience and support</i> .....	89
2.5	Discussion.....	91
2.5.1	Implications for policy and clinical practice .....	95
2.5.2	Strengths and limitations of the study .....	96
2.5.3	Recommendations for future research.....	97
2.6	Conclusion .....	99
2.7	References.....	100

## **CHAPTER 3 – REFLECTIVE PAPER**

### **Managing conflicts between personal and professional identities: a reflective account**

<b>3.1</b>	<b>Introduction .....</b>	<b>106</b>
<b>3.2</b>	<b>Acknowledging my position .....</b>	<b>107</b>
3.2.1	Reflexivity .....	107
3.2.2	Researcher background.....	107
3.2.3	Being an ‘outsider’ .....	108
3.2.4	Being an ‘insider’ .....	109
<b>3.3</b>	<b>Managing challenges with research methodology .....</b>	<b>111</b>
3.3.1	Recruitment .....	111
3.3.2	Finding a balance between roles .....	112
3.3.3	Data analysis and interpretation .....	113
<b>3.4</b>	<b>Closing the hermeneutic circle .....</b>	<b>116</b>
<b>3.5</b>	<b>Conclusion .....</b>	<b>117</b>
<b>3.6</b>	<b>References.....</b>	<b>118</b>

## List of Tables and Figures

Table 1	Search terms applied in the review
Table 2	Inclusion and exclusion criteria for studies
Figure 1	PRISMA flow diagram
Table 3	Characteristics of the identified studies
Table 4	Seven phases of meta-ethnography applied in the review
Table 5	Themes and concepts
Table 6	Distribution of themes and concepts across the identified studies
Table 7	Inclusion and exclusion criteria for participants
Table 8	Participant demographics
Table 9	Participants' symptoms and use of services
Table 10	Stages of interpretative phenomenological analysis applied in the study
Table 11	Super-ordinate themes and sub-ordinate themes
Table 12	Distribution of themes across participants

## List of Abbreviations and Symbols

BAME	Black, Asian and Minority Ethnic
CASP	Critical Appraisal Skills Programme
DoH	Department of Health
GP	General Practitioner
IPA	Interpretative Phenomenological Analysis
MUS	Medically Unexplained Symptoms
NIMHE	National Institute for Mental Health in England
NHS	National Health Service
$N$	Total number of participants
PICOS	Population, Intervention, Comparison, Outcome, Study type
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-analyses
QAR	Quality Assessment Rating
$\kappa$	Cohen's kappa inter-rater reliability coefficient
UK	United Kingdom



## List of Appendices

Appendix A – Search Strategy for Literature Review .....	119
Appendix B – Critical Appraisal Skills Programme Qualitative Checklist.....	125
Appendix C – Ethical approval from Coventry University .....	126
Appendix D – Ethical approval from the Health Research Authority .....	129
Appendix E – Ethical approval from Research & Development departments.....	130
Appendix F – Recruitment Poster .....	132
Appendix G – Participant Information Sheet .....	133
Appendix H – Consent Form.....	137
Appendix I – Demographic Questionnaire .....	138
Appendix J – Interview Schedule .....	140
Appendix K – Guide for Managing Risk .....	141
Appendix L – Debriefing Information Sheet .....	143
Appendix M – Example of an annotated transcript for IPA .....	145
Appendix N – Representation of themes for one participant .....	146
Appendix O – Visual mapping of themes across participants .....	147
Appendix P – Additional participant quotes .....	148
Appendix Q – Clinical recommendations from participants.....	152
Appendix R – Author Guidelines, Ethnicity & Health .....	154
Appendix S – Author Guidelines, Qualitative Health Research .....	157

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## Declaration

This thesis was carried out under the supervision of Dr Helen Liebling (Assistant Professor in Clinical Psychology, Coventry & Warwick Universities) and Dr Adam Cleary (Consultant Clinical Psychologist, Birmingham Community Pain Service). The content of this thesis is my own work, except where it contains work based on collaborative research, in which case the nature and extent of the author's individual contribution are indicated. This thesis has not been submitted for any other degree or to any other institution. The literature review will be submitted to the journal of *Ethnicity & Health* (Prajapati & Liebling). The empirical paper will be submitted to the journal of *Qualitative Health Research* (Prajapati, Liebling & Cleary).

## Summary

Chapter 1 is a systematic review of fifteen identified research studies, exploring the experiences of seeking help, and barriers to accessing and using mental health services in the United Kingdom, from the perspectives of South Asian service users. Three themes emerged from the meta-ethnographic synthesis: *Distanced from services*, *Dilemma of trust* and *Threat to cultural identity*. South Asian service users appeared to engage in an ongoing evaluation of the potential benefits of accessing services, against the risks of threat to their personal and cultural identities. Recommendations are made for services to implement a more culturally-safe and person-centred approach for South Asian service users.

Chapter 2 is a qualitative research study exploring the lived experiences of medically unexplained symptoms in six South Asian women. Interpretative phenomenological analysis of in-depth interviews resulted in three super-ordinate themes: *Multiple assaults on the self*, *Suffering in silence* and *Reconstructing the self*. Having endured traumatic experiences, the participants were marginalised from their communities and healthcare services, their needs were ignored, and their emotional distress silenced and medicalised. Recommendations are made for services to implement a more trauma-informed and holistic approach, acknowledging the emotional needs underlying the expression and lived experiences of medically unexplained symptoms in South Asian women.

Chapter 3 is a reflective paper, narrating the researchers' reflections on the process of undertaking the research project. The account reflects on managing research challenges and conflicts between personal and professional identities.

## **CHAPTER 1 – SYSTEMATIC LITERATURE REVIEW**

### **Access to mental health services: a systematic review and meta-ethnography of the experiences of South Asian service users in the UK**

This paper has been prepared for submission to *Ethnicity & Health*  
(See Appendix R for Author Guidelines)

Original word count (excluding abstract, tables, figures and references): 7,888

## 1.1 Abstract

Despite calls to address ethnic inequalities to accessing mental health services in the United Kingdom (UK), governmental initiatives have had limited impact. Studies indicate that South Asian communities under-utilise these services. Previous reviews have identified cultural and institutional factors that may influence service use, but these are mostly narrative and limited in their scope. A systematic literature search resulted in fifteen relevant studies exploring the experiences of seeking help and barriers to accessing and using services from the perspective of South Asian service users. Findings were synthesised using a meta-ethnographic approach and three themes emerged: *Distanced from services*, *Dilemma of trust* and *Threat to cultural identity*. South Asian service users felt positioned at a distance from being able to access services and stuck in a dilemma of mistrusting professionals from different ethnic backgrounds. They constructed their cultural identity through a set of important values, which were neglected in their interaction with mental health services. Service users, therefore, appeared to engage in an ongoing evaluation of the potential benefits of accessing services against the risks of threat to their personal and cultural identities. It is argued that cultural dissonance marginalises South Asian service users from access to appropriate services, as their personal and cultural needs are being ignored in healthcare encounters. It is recommended that services implement a more culturally-safe and person-centred approach, and acknowledge the impact of alienation and disempowerment in developing trusting relationships for South Asian service users in the UK.

## **1.2 Introduction**

### **1.2.1 Political and health context**

Mental health services recognise universal entitlement to adequate and appropriate healthcare for all residents of the United Kingdom (UK), as reflected in the National Service Framework for Mental Health (DoH, 1999). However, concerns about ethnic inequalities in access to mental health services have been rising over recent decades, leading to government initiatives to identify barriers and address disparities in outcome and experiences for different ethnic groups. This includes the policy document released by the National Institute for Mental Health (NIMHE, 2003) and Delivering Race Equality in Mental Health Care (DoH, 2005). This action plan aimed to achieve equality for Black, Asian and Minority Ethnic (BAME) service users by pledging that “everyone who experiences mental ill-health is entitled to a safe and clinically effective, recovery-enhancing environment that respects their beliefs, culture, faith, spiritual needs and values” (DoH 2005, p. 41).

Despite significant investment, outcomes from these programmes have failed to achieve lasting impact in areas of policy and service provision in the mainstream statutory sector (Fernando & Keating, 2008). The briefing Race Equality in Mental Health found there had been “little improvement in key measures of race equality” (NHS Confederation Mental Health Network, 2012, p. 2). This has been ascribed to the culture of the statutory sector which, appears stuck and “impervious to much change” (Fernando & Keating, 2008, p. 238). However, the failure of statutory services to meet the needs of BAME groups has been argued to constitute institutional racism, since it places them at disadvantage in

terms of attaining good health and standard of living compared to the majority population (McPherson, 1999).

### **1.2.2 Mental health of South Asian communities**

The ethnic category of 'South Asian' is used to refer to people whose familial or cultural backgrounds originate from countries on the Indian sub-continent, including India, Pakistan, Bangladesh, and Sri Lanka (Marshall & Yazdani, 2000). Although South Asian migrants have been settling in the UK since the 17<sup>th</sup> century (Visram, 2002), the current populations are largely the result of immigration following the Second World War from former British colonies or Commonwealth countries, encouraged by British colonial authorities due to post-war labour shortages (Peach, 2006; Watkins & Nurick, 2002). According to the UK census, 4.9% of the total population identify as South Asian, comprising the largest ethnic minority in the UK (Office of National Statistics, 2011).

There have been inconsistent findings in the literature regarding the prevalence of mental health problems in South Asian communities. Early epidemiological studies reported lower rates of psychological distress in South Asian groups compared to White groups (Bhui, 1999; Cochrane & Stopes-Roe, 1977; Nazroo, 1997). More recent studies have suggested that South Asian people have higher levels of psychological distress compared to the White majority. For example, a large-scale household survey of psychiatric morbidity in England found rates of common mental disorders, such as depression and anxiety, to be 13-15% higher in South Asian women compared to Black or White women (McManus, Meltzer, Brugha, Bebbington & Jenkins, 2007). Figures also suggest a higher rate of self-harm and suicide in young women from a South Asian background compared to White women (Ineichen, 2012). However, these studies have been criticised for employing small sample sizes, culturally-inappropriate measures, and conceptualisations



of distress based on Western ideals (Anand & Cochrane, 2005; Williams, Eley, Hunt & Bhatt, 1997).

### **1.2.3 Help-seeking and access to mental health services**

Although literature regarding the prevalence of mental health problems in British South Asian communities has been inconclusive, findings suggest that these groups utilise mental health services less than other ethnic groups (Fazil & Cochrane, 2003; NIMHE, 2004). A number of factors have been suggested to account for these differences. Alexander (2001) argues that a lack of information and awareness presents as a barrier to accessing mental health services. Some research has also identified that General Practitioners (GPs) are less likely to detect mental health problems in South Asian groups compared to other ethnic groups (Bhui, Bhugra, Goldberg, Dunn & Desai, 2001). Since GPs are important gatekeepers for specialist mental health services, their failure to detect mental health difficulties amongst South Asian people can hinder access to appropriate services (Netto et al., 2001).

Other researchers implicate the role of help-seeking behaviours in South Asian communities (Kirmayer & Bhugra, 2009). Help-seeking can be defined as “attempts to maximise wellness or to ameliorate, mitigate, or eliminate distress” (Saint Arnault, 2009, p. 260). Since the “culturally-acquired psyche” is deeply entrenched within a person’s beliefs, thoughts and behaviours (Laungani, 2005, p. 250), culturally-informed views influence the understanding of distress, help-seeking, and healthcare utilisation in migrants (Selkirk, Quayle & Rothwell, 2014). This is found in many cultures, where traditional ways of understanding and healing persist (Sue & Sue, 2012). The Cultural Determinants of Help-Seeking model offers a framework to understand help-seeking across cultures (Saint Arnault, 2009). It postulates that emotional or physical sensations are filtered through cultural explanatory models regarding wellness and distress. When distress is

perceived, its social significance and consequences are evaluated. If the distress is evaluated as negative, individuals may perceive shame or stigma, which could hinder help-seeking.

Previous reviews have identified cultural factors that may influence help-seeking for South Asian groups. Anand and Cochrane (2005) identified collectivist values, pluralistic treatment options, acculturative stress, and shame as factors that led South Asian women to construe their psychological problems differently to White women, leading to lower use of mainstream services. Ineichen (2012) found that the attitudes of South Asian service users towards mental illness were affected by religious beliefs, somatisation, and stigma. Utilising a systematic review process, Kapadia and colleagues (2017) argued that Pakistani women were less likely to use specialist mental health services, but experienced high levels of isolation. Potential reasons for lower utilisation included stigma, a preference for Pakistani health professionals, and inadequate services, including language barriers.

Access to appropriate healthcare can, therefore, be conceptualised through ‘candidacy’, where people’s eligibility for professional attention and intervention is jointly negotiated between individuals and healthcare services (Dixon-Woods et al., 2005). Services can be constructed through a spectrum of permeability, where ‘high’ permeability services are culturally-sensitive and more easily negotiated, whereas ‘low’ permeability services demand more work, are more resistant and present more barriers. It has been argued that South Asian groups are at risk in their attempts to assert their candidacy, due to socio-economic, cultural, and institutional exclusion from statutory healthcare services (Bowl, 2007; McLean, Campbell & Cornish, 2003).

#### **1.2.4 Rationale for the current research**

Research exploring ethnic inequalities in mental health has predominantly used epidemiological approaches. Although this has shed light on the different pathways into services, it ignores the social and cultural contexts in which mental health problems arise (Fernando & Keating, 2008), and provides no depth of understanding from South Asian service users (Bowl, 2007).

Qualitative approaches are vital for addressing health inequalities and shaping healthcare services (Ring, Ritchie, Mandava, & Jespon, 2010). It has been recommended that primary care trusts and local authorities engage with BAME communities to ensure that “care and recovery planning processes include service users’ perspectives of their needs” (DoH, 2005, p. 48). However, the views and experiences of South Asian service users have been neglected in qualitative research; where their views have been represented, they are often amalgamated with other ethnic groups or with professionals and service providers, undermining the importance of their views.

Furthermore, existing literature on the views of South Asian service users has focused on specific mental health problems or inpatient settings (Milsom, 2014). Since 90% of people with mental health problems are treated in primary care (DoH, 2005), research also needs to focus on community settings (Brown et al., 2014; Lloyd, 2006).

To date, no reviews have systematically synthesised the literature on South Asian adults’ experiences of seeking support for mental health problems in primary care settings in the UK, or their perceptions of barriers to accessing these services.

### **1.2.5 Aims and objectives**

This literature review aims to identify and systematically review the qualitative evidence on the experiences of South Asian adults when accessing mental health services. It has two primary questions:

- What experiences do South Asian service users have of accessing mental health services in the UK?
- What do South Asian service users perceive as barriers to accessing mental health services in the UK?

The method of meta-ethnography was employed to synthesise the qualitative evidence. It is hoped the review will enable a deeper understanding of the experiences of South Asian service users, in order to inform the shape of future service design and improve person-centred care (Ring, Ritchie, Mandava, & Jespon, 2010).

## **1.3 Method**

### **1.3.1 Systematic literature search**

#### *1.3.1.1 Search strategy*

A comprehensive literature search was carried out to identify relevant primary research studies conducted in the UK from 1999 to 2019. This time period was chosen because the National Service Framework for Mental Health (DoH) set out key targets for improving access to mental health services in 1999, highlighting that mental health problems were frequently overlooked in BAME communities and that people from BAME communities were less likely to be referred to psychological therapies. This coincided with the Race Relations Act (Amendment) Act 2000, which made it unlawful to discriminate on the basis of race, ethnicity or culture, and placed responsibility on public bodies such as the NHS to target racial discrimination and actively promote equality.

The following electronic research databases were searched: PsycINFO, MedLine, Embase, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Web of Science, and the Applied Social Sciences Index and Abstracts (ASSIA). Relevant grey literature databases were also searched to locate unpublished material, including Open Grey, IRUS UK, Bielefeld Academy Search Engine (BASE), EThOS, Open Access Theses and Dissertations (OATD), and Social Care Institute for Excellence (SCIE) Online. In line with previous recommendations for conducting a meta-ethnography, additional articles were identified by searching through the citations of selected articles and literature reviews, reviewing references lists, and hand-searching relevant books and journals (Atkins et al., 2008; Ring et al., 2010).

### 1.3.1.2 *Search terms*

The PICOS framework was used to structure the search across research databases. This framework is a modified version of the popular PICO tool, which focuses on the Population, Intervention, Comparison, and Outcome of an article, with additional terms for the Study design to limit the number of irrelevant articles. The PICOS tool has shown to be effective for reviews of qualitative studies (Methley, Campbell, Chew-Graham, McNally & Cheraghi-Sohi, 2014). Table 1 outlines the search terms that were applied to the PICOS framework; these terms were used consistently in all research databases, in addition to location terms to retrieve more relevant results. In line with previous recommendations for conducting a meta-ethnography, free-text search terms were used as well as subject headings, and both title and abstract fields were applied in all searches (Atkins et al., 2008; Ring et al., 2010).

In order to broaden the scope of the search, special characters were used. The truncation symbol (\*) was used to search for variable word endings, e.g. therap\* for therapy, therapeutic and therapies, and wildcard symbols (? or #) were used to capture variable word spellings, e.g. help?seeking for help seeking and help-seeking. Boolean operators OR/AND were applied to combine the search terms within the PICOS framework. Appendix A reveals the search terms and special characters applied for each research database.

Table 1. Search terms applied in the review.

	Concept	Synonyms	Location
<b>Population</b>	South Asian ethnicity	South Asian, Asian, Bangladeshi, Bengali, Gujarati, Indian, Sri Lankan, Pakistani, Punjabi	Title Abstract Keywords Subject headings
<b>Intervention</b>	Mental health and/or mental health services	mental health, mental illness, mental disorder, emotional distress, psychological distress, mental health services, psychological services, primary care, community mental health services, psychotherapy, therapy, counselling	Title Abstract Keywords Subject headings
<b>Comparison</b>	N/A		
<b>Outcome</b>	Help-seeking and barriers to service use	acceptability, access, accessibility, barriers, challenges, engagement, exclusion, hindrance, limitations, obstacles, pathway, use, utilisation, help-seeking, seeking support	Title Abstract Keywords Subject headings
<b>Study type</b>	Qualitative	qualitative, interview, focus group, content analysis, discourse analysis, ethnography, grounded theory, mixed methods, narrative, phenomenological, thematic analysis	Title Abstract Keywords Subject headings
<b>Location</b>	United Kingdom	England, Scotland, Wales, Northern Ireland, United Kingdom, Great Britain	Title Abstract Keywords Subject headings

### 1.3.1.3 Inclusion and exclusion criteria

The results were screened for eligibility according to the review's inclusion and exclusion criteria (Table 2). Where this was not possible due to insufficient information in the abstract, full-text articles were obtained and assessed against the criteria. These were sought through institutional login and contacting specialist subject librarians for further assistance. An inclusive approach was employed to avoid omitting research of potential value (Atkins et al., 2008).

Table 2. Inclusion and exclusion criteria for studies.

	Inclusion criteria	Exclusion criteria
<b>Location</b>	Conducted in the UK	Conducted in any country other than the UK
<b>Time period</b>	Published between 1999 and 2019	Published before 1999
<b>Methodology</b>	Qualitative methodology for data collection and analysis	Quantitative methods
<b>Population</b>	South Asian participants (Indian, Pakistani, Bangladeshi) whose data was analysed separately	Studies which combined data of South Asian participants with participants from other ethnic groups
	Potential or actual service users	Family members, healthcare professionals or community leaders
<b>Age</b>	Adults (aged over 18 years)	Children or adolescents
<b>Concepts</b>	Experiences of seeking help in statutory mental health services	Not relevant to issues of access or use of statutory mental health services
	Barriers to accessing statutory mental health services	Focused on a specific service or intervention
<b>Article</b>	Original research article	Not an original research article, e.g. review, report, book chapters
<b>Language</b>	Article written in English	Article written in language other than English

#### 1.3.1.4 Search outcome

The systematic process of identifying and selecting articles for inclusion in the review was recorded on a Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) flow diagram (The PRISMA Group, 2009). In total, 2,569 records were identified through the database search, and 493 records through a search of the grey literature, resulting in 3,062 records. All records were imported into RefWorks reference management software for management. After eliminating duplicates, the titles and abstracts of 2,042 records were manually screened against the inclusion and exclusion criteria. Based on this, 1,885 articles were excluded. The full text for the remaining eligible 157 articles were reviewed according to the inclusion and exclusion criteria, and a further



140 excluded as they were not directly relevant to the review aims. Two articles could not be retrieved due to institutional restrictions. This resulted in fifteen relevant studies which satisfied the inclusion criteria and were retained for quality assessment. Figure 1 shows the process of study selection and exclusion with reasons.

Given that the aim was to provide a depth of insight into the help-seeking experiences and barriers perceived by South Asian service users, the number of included studies allowed for a rich description of experiences and conceptual clarity. In practice, 8-13 studies are considered appropriate for a qualitative synthesis of this depth (Ring et al., 2010).

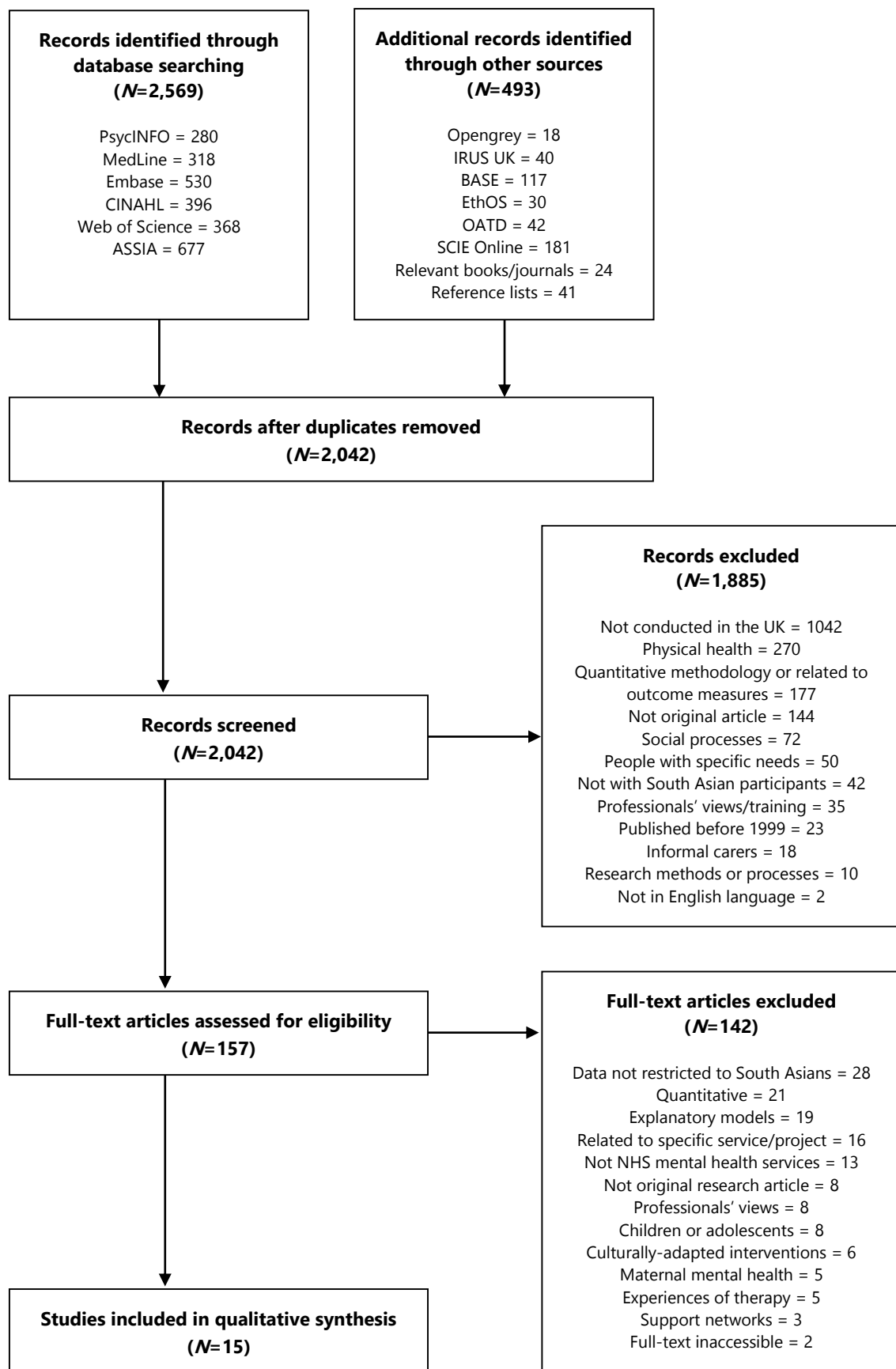


Figure 1. PRISMA flow diagram (The PRISMA Group, 2009).

### 1.3.2 Quality appraisal

There is considerable debate regarding the use of quality appraisal tools within qualitative research since there is no consensus about what makes a study 'good' (Toye et al., 2014). Judgments about the methodological quality of studies are often subjective, and strict adherence to appraisal guidelines may lead to insightful studies with minor methodological flaws being excluded (Campbell et al., 2011). Therefore, the purpose of quality appraisal in this systematic review was to enhance understanding of the results in each study and give an indication of their relative strengths, not to indicate exclusion.

The quality assessment tool devised by the Critical Skills Appraisal Programme (CASP, 2018) was used to appraise the quality of the fifteen identified studies. This is a structured quality appraisal tool which considers key methodological components relevant to qualitative research using ten criteria (Appendix B). The CASP tool was chosen as it has been developed and tested over a period of time (Campbell et al., 2011), has been used by a number of researchers to appraise the quality of research studies for meta-ethnography (Atkins et al., 2008; Campbell et al., 2003; Pound et al., 2005), and has shown to be effective in achieving this purpose (Toye et al., 2014).

Each study was assessed against the ten criteria using a rating system where 0 = criterion not met, 1 = criterion partially met, and 2 = criterion fully met (Little, Tickle, & Nair, 2018). Similar to the practice of other researchers (Carolan, Smith, Davies & Forbat, 2018; Kanavaki et al., 2017), the quality of studies was assessed by the overall rating rather than employing a cut-off score, where high quality = 16-20, medium quality = 11-15, and low quality = 0-10. This allowed for all relevant studies to be included in the review. Each study was rated by the author and an independent reviewer, and inter-reliability was assessed using Cohen's kappa ( $\kappa$ ) coefficient. Quality assessment ratings (QARs) ranged

from 15-20 indicating that studies were of medium-high quality. Significant discrepancies between ratings were discussed to improve inter-rater reliability. The final reliability coefficients ranged from  $\kappa=.615$  to  $\kappa=1$  (Table 3), with an overall score of  $\kappa=.852$ . This represents a moderate-strong pattern of inter-rater reliability (Altman, 1999).

### **1.3.3 Characteristics of the literature**

Studies varied in the information they provided regarding sample demographics. Several studies did not report the participants' ethnicity (Bhui, Chandran & Sathyamoorthy, 2002; Gilbert, Gilbert & Sanghera, 2004; Hussain & Cochrane, 2002; Hussain & Cochrane, 2003), age (Hussain & Cochrane, 2002; Hussain & Cochrane, 2003) or generational status (Bowl, 2007; Chew-Graham, Bashir, Chantler, Burman & Batsleer, 2002; Gilbert, Gilbert & Sanghera, 2004; Hussain, 2006; Kai & Hedges, 1999; Thompson, 2010), and one study did not report the sample size (Gilbert, Gilbert & Sanghera, 2004). Two studies were conducted using the same sample so were only counted once, although both contributed to the analysis as they covered different topics (Hussain & Cochrane, 2002; Hussain & Cochrane, 2003).

Based on the data provided, the following demographics were identified (Table 3). Service users ranged from 16 to 70 years in age and comprised of 280 females and 125 males in total. Participants identified their ethnicity as Indian, Pakistani or Bangladeshi, and reported religious or faith traditions as Islam, Hinduism or Sikhism. Whilst three studies focused on second-generation adults (Moller, Burgess & Jogiyat, 2016; Sudan, 2004; Wood, 2011), most included a combination of first and second-generation South Asian adults.

Eight studies included clinical samples with experiences of statutory services in the community (Bhui, Chandran & Sathyamoorthy, 2002; Bowl, 2007; Hussain & Cochrane, 2002; Hussain & Cochrane, 2003; Hussain, 2006; Sudan, 2004; Thompson, 2010; Wood, 2011), whilst seven studies explored the perspectives of South Asian people with no prior experiences of seeking professional help (Chew-Graham et al., 2002; Gilbert, Gilbert & Sanghera, 2004; Kai & Hedges, 1999; Mahmood, 2012; Moller, Burgess & Jogiyat, 2016; Patel, 2016; Ruprai, 2016). The attitudes and beliefs of 'lay people' may not correspond with their actual intent or behaviour, but offered the perspectives of those who could potentially experience emotional distress and require support from services. Clinical samples reported experiencing depression, anxiety, self-harm, schizophrenia and psychosis. In three studies, participants had been in contact with community and inpatient services (Bhui, Chandran & Sathyamoorthy, 2002; Bowl, 2007; Sudan, 2004); where possible, only their experiences relevant to community settings were included. For ease of reading, both potential and actual service users are referred to as 'service user' in this review.

Studies predominantly employed individual semi-structured interviews to collect data. Three studies conducted focus groups (Bowl, 2007; Chew-Graham et al., 2002; Gilbert, Gilbert & Sanghera, 2004), whilst one study used open-ended questionnaires (Moller et al., 2016). These latter methods may have influenced the data collected since participants were not given the opportunity to explore their individual views. Furthermore, variable information was provided about the methodological process. Some studies gave minimal information about their analytic procedure (Bhui, Chandran & Sathyamoorthy, 2002; Chew-Graham et al., 2002; Gilbert, Gilbert & Sanghera, 2004), while others gave little consideration to researcher reflexivity (Bhui, Chandran & Sathyamoorthy, 2002; Bowl,

2007; Chew-Graham et al., 2002; Gilbert, Gilbert & Sanghera, 2004). This made it difficult to assess the rigour and validity of their qualitative analysis.

Nine studies were published journal articles (Bhui, Chandran & Sathyamoorthy, 2002; Bowl, 2007; Chew-Graham et al., 2002; Gilbert, Gilbert & Sanghera, 2004; Hussain & Cochrane, 2002; Hussain & Cochrane, 2003; Hussain, 2006; Kai & Hedges, 1999; Moller, Burgess & Jogiyat, 2016), while six studies were unpublished doctoral theses identified in the grey literature (Mahmood, 2012; Patel 2016; Ruprai, 2016; Sudan, 2004; Thompson, 2010; Wood, 2011). Although the unpublished doctoral theses were not peer-reviewed to the same extent as the published articles, overall they were of higher quality as indicated by their QARs.

The final fifteen studies represented the experiences of four hundred and five South Asian service users from different geographical regions of England. Key findings relevant to the aims of the review are shown in Table 3.

Table 3. Characteristics of the identified studies.

Author(s) Study aims	Sample demographics	Study methodology and characteristics	Main relevant findings	QAR and reliability coefficient ( $\kappa$ )
<b>Bhui, Chandran &amp; Sathyamoorthy (2002)</b>				
To understand South Asian men's perceptions of mental health assessment, and to explore the quality of care available to male Asian service users.	N=8 All male Age range 19-62 4 Indian, 2 Pakistani, 2 unclear 7 first-generation, 1 second-generation Conducted in South London	Actual service users; Purposive sampling from statutory and voluntary mental health services; Individual semi-structured interviews; Analysed using thematic analysis Published article	Eight themes were found: (1) Clinical contact, (2) Professional role, (3) Language and interpreters, (4) Ethnicity and gender, (5) Religion and culture, (6) Understanding the problem, (7) Reflection on assessment, and (8) Treatment. Professionals often did not explain their role or the process of assessment. Participants spoke English to different levels but were assessed in English. They were not given a choice about the ethnicity/gender of the professional, but some participants had clear preferences. Participants were not satisfied with the explanations given, had limited opportunity to discuss their perspective of the problem, and were not satisfied with the treatment recommended. None were given a chance to discuss their religion/culture, yet all felt this would have been useful.	QAR=17 $\kappa=.756$
<b>Bowl (2007)</b>				
To gain the specific views of South Asian service users about their interactions with mental health services and their perceived limitations.	N=26 11 male, 15 female Age range 21-60+ Pakistani or Indian Generational status unclear Conducted in Birmingham	Actual service users; Opportunistic sampling from statutory and voluntary mental health services; Three focus groups (8 males, 7 females, 8 females respectively); Notes analysed using thematic analysis Published article	Four themes were found: (1) Socio-economic exclusion, (2) Cultural exclusion, (3) Institutional exclusion, and (4) Wider views on services. Many participants identified links between their mental health problems and socio-economic exclusion i.e. loss of employment and money. Many participants felt that their language needs were neglected, that assessments were not culturally relevant, and that facilities were not provided for prayer, leading to cultural exclusion. They reported concerns that family were not involved in their care or that effort was not made to share knowledge about medications. Participants had strong support for resources targeted at South Asian service users and a view that commissioners were not doing enough to meet that need or engage them in decision-making.	QAR=16 $\kappa=.783$

Note: QAR = quality assessment rating as rated according to the Critical Skills Appraisal Programme quality appraisal tool (CASP, 2018).

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**Chew-Graham, Bashir, Chantler, Burman & Batsleer (2002)**

To explore South Asian women's perceptions and experiences of mental distress, attempted suicide/self-harm, and barriers preventing access to services.	<i>N</i> =31 All female Age range 17-50 Pakistani, Bangladeshi, Indian Generational status unclear Conducted in Manchester	Potential service users; Purposive sampling from voluntary women's groups in the community; Four focus groups (with 5, 7, 7 and 12 participants respectively); Analysed using framework analysis Published article	Ten themes were found: (1) Izzat, (2) Community grapevine, (3) Racism, (4) English-language problems, (5) Psychological distress as a symptom of external pressures, (6) Attempted suicide and self-harm as a response to social isolation, (7) Domestic violence and consequences of leaving the family, (8) Differences within communities, (9) Access to mainstream service provision, and (10) Improving service provision. The importance of izzat (family honour and reputation) in Asian culture and family life was described, resulting in a need to protect izzat. A well-developed community grapevine often led to oppression and stigma from the community. Inability to speak English led to a lack of knowledge of services and support, while sexism and racism exacerbated the participants' sense of isolation. All participants said trust was important to access mainstream services. Barriers included a lack of understanding of the Asian culture, providers being mostly White, issues with interpreters, fear of gossip, lack of awareness of services provided, and little ethnic-matching.	QAR=16  κ=.808
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**Gilbert, Gilbert & Sanghera (2004)**

To explore South Asian women's views on shame, subordination and entrapment, and how these might affect mental health problems, help-seeking, and the use of services.	<i>N</i> =Not stated All female Age range 16-41+ Ethnicities not stated Generational status unclear Conducted in Derby	Potential service users; Purposive sampling from a voluntary service; Three focus groups of different ages (16-25, 26-40, 41+) in which four scenarios were presented and questions posed; Method of analysis not stated Published article	Six categories were listed, four of which related to the four scenarios presented: (1) Izzat scenario, (2) Shame scenario, (3) Subordination scenario, (4) Entrapment scenario, (5) Effects on mental health, and (6) Help-seeking behaviour. Participants felt that help-seeking was influenced by fear of discovery, confidentiality and feeling ashamed. Participants did not know what services were available, and were undecided on the benefits of seeing a White professional due to fears of being misunderstood.	QAR=17  κ=.778
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**Hussain & Cochrane (2002)**

To explore the thoughts, feelings and beliefs of South Asian women on causes and cures for their depression, and the implications for mental health services.	<i>N</i> =13 All female Age range and ethnicities not stated 9 first-generation, 4 second-generation Conducted in Birmingham	Actual service users; Non-probabilistic sampling from statutory mental health services; Individual semi-structured interviews; Analysed using grounded theory Published article	Three categories were identified: (1) Conflicting cultural expectations, (2) Distinctions between psycho-social, spiritual and physical problems, and (3) Communication problems (general and culture-specific). Participants reported that communication problems led to a lack of information, affected professionals' interpretation of their problems, and resulted in a lack of opportunity to access counselling/psychotherapy. They described minimal distinctions between psycho-social, spiritual and physical problems, leading to confusion over cause and subsequent treatment options, but also conflict with the restricted perspectives of mental health services.	QAR=18  κ=.706
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**Hussain & Cochrane (2003)**

To explore beliefs and attitudes around coping and the strategies employed by South Asian women, and the relationship between coping and treatment.	<i>N</i> =13 All female Age range and ethnicities not stated 9 first-generation, 4 second-generation Conducted in Birmingham	Actual service users; Non-probabilistic sampling from statutory mental health services; Individual semi-structured interviews; Analysed using grounded theory Published article	One core category was found: Coping strategies used and factors affecting choice. Coping strategies included praying/religion, herbal remedies, talking, self-harm or crying. Factors affecting the degree of coping were the perception of the problem, the existence of motivating factors, and access to help. Some participants felt they did not need to look externally for support and could cope by themselves, whereas others felt that external support was not available to them. Where support was identified, its use depended on weighing up the benefits of receiving community help against the problems this may cause.	QAR=17  κ=.706
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<b>Hussain (2006)</b>				
To understand the perceptions and experiences of Punjabi immigrants on accessing mental health services.	<p><i>N</i>=33</p> <p>16 male, 17 female</p> <p>Age range 55-62</p> <p>All Punjabi</p> <p>Generational status unclear</p> <p>Conducted in North England</p>	<p>Actual service users;</p> <p>Purposive sampling from statutory mental health services or traditional healers;</p> <p>Individual semi-structured interviews;</p> <p>Analysed using grounded theory</p> <p>Published article</p>	<p>Eight categories were identified: (1) A comprehensive understanding of the narratives of health and the experience of service use, (2) Punjabis' beliefs regarding distress, (3) Distress: causes and remedies, (4) Kismet: fate as the cause of distress, (5) Sabr: endurance of distress as help-seeking, (6) Purdah: gender modesty and role-fulfilment as the determinant activity in distress and it's amelioration, (7) Izzet: honour and family protection as the measure of balanced mental health, and (8) 'Peace of mind': normal mental health and its cultural formulation.</p> <p>The participants' understanding of distress was encapsulated by their cultural and religious values (kismet, sabr, izzat and purdah), which were incongruent with Western concepts. The use and experience of statutory services were filtered through the lens of these values, creating expectations of the means/content of service delivery that were incompatible with mainstream services. This led to confusion, alienation, or further distress for both the participant and the provider, creating barriers to appropriate care.</p>	<p>QAR=19</p> <p><math>\kappa=1</math></p>
<b>Kai &amp; Hedges (1999)</b>				
To explore Pakistani and Bangladeshi service users perceptions of distress and its amelioration, in order to develop services appropriate to their needs.	<p><i>N</i>=104</p> <p>38 male, 66 female</p> <p>Age range 16-65+</p> <p>49 Pakistani, 55 Bangladeshi</p> <p>Generational status unclear</p> <p>Conducted in Newcastle</p>	<p>Potential service users;</p> <p>Snowball sampling from community networks;</p> <p>Individual semi-structured interviews facilitated by trained community project workers;</p> <p>Method of analysis not stated</p> <p>Published article</p>	<p>Eight categories were listed: (1) Racism, social disadvantage and distress, (2) Coping with distress, (3) Family relationships, (4) Seeking help from professionals, (5) Younger people, (6) Community Project Workers' experiences, (7) Experiences of project steering group and costs, and (8) Subsequent service development,</p> <p>Most participants located their main sources of distress within their external social environment, related to racism, social disadvantage and distress. Some also raised their family and marital relationships as causes of distress, worry or sadness. A majority of participants felt that health professionals and GPs were unable to deal with worry or stress, defining their roles in terms of physical health. Most wanted to seek help from those who they felt would have understanding and empathy due to a shared background/culture, but they emphasised breach of confidentiality as a potential barrier.</p>	<p>QAR=18</p> <p><math>\kappa=1</math></p>

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**Mahmood (2012)**

To explore the experiences and needs of Punjabi Pakistani immigrants with psychological distress, and their views on using mental health services.	<i>N</i> =7 All male Age range 21-35 Punjabi Pakistani All first-generation Conducted in London	Potential service users; Convenience and snowball sampling from community centres; Individual semi-structured interviews; Analysed using IPA Unpublished doctoral thesis	Two super-ordinate themes were found: (1) On being masculine and (2) The unknown territory of counselling. Participants described avoidance of confronting a weaker/vulnerable part of themselves, through self-reliance, presenting a strong image, and restricting emotional expression. They also emphasised their lack of awareness of counselling services. Shame and stigma were attached to mental health, so participants had no strong motivations to access psychological services, instead, seeing therapy as a last resort.	QAR=19  $\kappa=1$
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**Moller, Burgess & Jogiyat (2016)**

To explore barriers to counselling and help-seeking in second-generation South Asian women.	<i>N</i> =82 All female Age range 18-40 34 Indian, 20 Pakistani, 10 Mixed/Other All second-generation Conducted in North England	Potential service users; Opportunity sampling from community centres; Open-ended questionnaires; Analysed using thematic analysis Published article	One overarching theme of 'Stereotyping' was found, with four sub-ordinate themes: (1) White counsellors are..., (2) Asian counsellors are..., (3) Counselling is..., and (4) People with psychological problems are.... Participants held stereotypes about White and Asian counsellors which affected their choices to seek help. They saw White counsellors as culturally ignorant, yet non-judgmental, and Asian counsellors as untrustworthy, yet understanding of cultural issues. Their choice depended on the nature of the problem they were to seek help for. Participants felt that counsellors were limited in their ability to effect change, and saw counselling as an 'abnormal' practice which brought shame and stigma to the family, as people were psychological problems were themselves stigmatised as 'mad'.	QAR=18  $\kappa=.615$
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**Patel (2016)**

To explore how the Indian Gujarati community understand mental health and make sense of help-seeking for mental health problems.

*N*=9  
4 male, 5 female  
Age range 24-65  
All Indian Gujarati  
4 first-generation, 5 second-generation  
Conducted in London

Potential service users;  
Opportunistic and snowball sampling from community centres and temples;  
Individual semi-structured interviews;  
Analysed using thematic analysis  
Unpublished doctoral thesis

Five themes were found: (1) Constructions and causes of mental health problems, (2) Religion: An integral role, (3) Community: A means of support and safety, (4) Family: Honour and reputation, and (5) Professional services: Challenges and vision.  
Participants perceived religion as integral to their daily life, and a vital coping resource/protective factor. Family were often the first source of support for participants; they talked about the significance of protecting family honour by not sharing problems with others. The community was positioned as having a unique role in providing support, which participants saw as being central in seeking help for mental health difficulties. A number of barriers to help-seeking were reported, including a lack of cultural sensitivity, language issues, fear of gossip, damage to marriage prospects, and a lack of trusting relationship with professionals. Many felt that services needed to make links with community/faith groups to overcome these barriers.

QAR=18

$\kappa=1$

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**Ruprai (2016)**

To explore beliefs about psychological wellbeing and an understanding of mental health issues in the Punjabi Sikh community.

*N*=8  
4 male, 4 female  
Age range 28-70  
All Punjabi  
8 first-generation, 3 second-generation  
Conducted in West London

Potential service users;  
Opportunistic and snowball sampling from community centres and temples;  
Individual semi-structured interviews;  
Analysed using thematic analysis  
Unpublished doctoral thesis

Three themes were found: (1) We are Warriors!, (2) The Importance of Family Expectations, and (3) Understanding Mental Health Issues.  
Participants were strongly influenced by their Sikh history and believed that they were capable of managing hardships without the input of external services. They believed that families should support each other through times of misfortune and that they do not suffer from 'ill mental health', so did not see mental health services as relevant to them.

QAR=19

$\kappa=1$

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**Sudan (2004)**

To explore how South Asian men perceive their culture within a mental health context, and to explore their perspective of having a psychiatric diagnosis and its implications.

*N*=6  
All male  
Age range 30-40  
Pakistani, Indian  
All second-generation  
Conducted in Leicester

Actual service users;  
Purposive sampling from statutory mental health services;  
Individual semi-structured interview;  
Analysed using grounded theory  
Unpublished doctoral thesis

One overarching category of 'Reconstructing a sense of identity' was found, with five main themes: (1) Identification with Asian culture and values, (2) Contact and experience of the mental health system, (3) Identity not being heard, (4) Others influencing the formation of separate identities, and (5) Others influencing the integration of identities. Participants felt that their Asian identity was not being heard by statutory services and questioned dominant beliefs about the origins and consequences of illness. Other people, including family and statutory services, were important in influencing the formation or integration of their identities.

QAR=19

$\kappa=1$

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**Thompson (2010)**

To discover what second-generation Asians of Sikh faith require from older adult psychological services to promote their psychological health and wellbeing.

*N*=73  
31 males, 42 females  
Age range 45-65  
All Asians of Sikh faith  
Generational status unclear  
Conducted in Sandwell

Actual service users;  
Purposive and snowball sampling from statutory mental health services and community organisations;  
Individual semi-structured interviews;  
Analysed using IPA  
Unpublished doctoral thesis

Eight main themes were found: (1) Cultural and contextual background, (2) The significance of religion in health and healthcare, (3) Individual strategies for managing distress, (4) Individual strategies for enhancing quality of life, (5) Challenges to quality of life in old age, (6) Limited service provision, (7) All psychological services are potentially useful for this generation/community, and (8) Service delivery considerations for the Sikh community. Good health was seen as a shared responsibility between God and the person. Religious coping strategies such as prayer and meditation were significant, and participants kept busy and active through their roles in the family and community. Participants wanted services to account for religious beliefs, show persistent demonstrations of interest and concern to help them feel valued and looked after. Challenges to the uptake of services included fear of gossip and the importance of confidentiality. Aids to support seeking included publicity, familiarity and encouragement.

QAR=19

$\kappa=1$

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**Wood (2011)**

To explore the experiences and meanings of South Asian women who self-harm, and their experiences and perceptions of support services.

N=5

All female

Age range 20-35

4 Pakistani, 1 Bangladeshi

All second generation

Conducted in Leeds

Actual service users;  
Purposive sampling from statutory mental health services and community groups;  
Individual semi-structured interviews;  
Analysed using IPA  
Unpublished doctoral thesis

Participants' accounts were analysed individually, but three themes were identified at the group-level: (1) Control, (2) Communication, and (3) Identity. Participants felt unable to express themselves due to feeling controlled by others, and experienced conflict regarding their sense of self. They expressed fear of judgment as a barrier to sharing their distress; this was related to potential responses to their self-harm and the ethnicity of professionals. Service responses sometimes inadvertently replicated the patterns in their previous interactions and consequently exacerbated their distress.

QAR=19

$\kappa=1$

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### **1.3.4 Analytic review strategy**

Meta-synthesis refers to a collection of different methods for systematically reviewing and integrating findings from qualitative studies (Lachal, Revah-Levy, Orri & Moro, 2017). Meta-ethnography was chosen as the synthesis method for this review as it offers a means of rigorously synthesising qualitative research to provide a “range and depth of meanings, experiences, and perspectives of participants across healthcare contexts” (Tong, Fleming, & McInnes, 2012, p. 1). It allows for a higher level of analysis compared to conventional literature reviews by enabling the construction of an interpretative layer which extends beyond the interpretations provided by the included studies (Cahill et al., 2018). Such a synthesis can achieve greater conceptual understanding and make valuable knowledge accessible to healthcare professionals, in line with the aims of this review (Atkins et al., 2008; Toye et al, 2014). To achieve this, the seven phases of meta-ethnography outlined by Noblit and Hare (1988) were implemented in an iterative manner (Table 4).

Table 4. Seven phases of meta-ethnography applied in the review (Noblit & Hare, 1988).

Phase	Description
<b>Getting started</b>	The initial focus of interest was on the help-seeking experiences of South Asian service users and barriers to accessing mental health services.
<b>Confirming initial interest</b>	After scoping the literature and discussion with the research team, the initial interest was refined to studies in primary care or community settings, and restricted to adults. A decision was made to include studies with non-clinical samples, as it was felt this could shed light on the barriers for 'potential' service users.
<b>Reading the studies and extracting data</b>	The resulting fifteen studies were read and re-read with close attention to identify ideas or metaphors relevant to the review aims. These initial 'concepts' were noted in the original studies.
<b>Determining how the studies are related</b>	Concepts were entered into a table to enable comparison, whereby the concepts were entered into rows and the identified studies were entered into columns in chronological order. The original list of concepts were: lack of information/awareness, lack of collaborative care, preferences, mistrust of professionals, professionals not equipped, fear of breach of confidentiality, fear of being misjudged, fear of stigma, lack of cultural sensitivity, cultural differences, family privacy and honour, importance of language, and importance of religion.
<b>Translating the studies</b>	Using the table, concepts were compared within and across studies, referring to the original text where necessary, to develop concepts that represented "meaningful ideas that explain and not just describe the data" (France et al., 2014, p. 9). A process of 'translation' enabled related concepts to be merged or revised, while others were reduced, giving rise to the final six concepts: <i>Outside of awareness</i> , <i>Outside of cultural norms</i> , <i>Cannot trust non-Asian professionals</i> , <i>Cannot trust Asian professionals</i> , <i>Lack of cultural sensitivity</i> and <i>Lack of collaborative care</i> .
<b>Synthesising translations</b>	The six derived concepts were then further reviewed to establish the relationships between them; it appeared that they were not refutations of one another, but were reciprocal. This enabled a 'line of argument' synthesis to be developed, which involved putting the concepts into interpretative order to make "a whole into something more than the parts alone imply" (Noblit & Hare, 1988, p. 28).
<b>Expressing the synthesis</b>	The six concepts were abstracted into three themes which comprised the final synthesis as follows: <i>Distanced from services</i> , <i>Dilemma of trust</i> , and <i>Threat to cultural identity</i> (Table 5).



## 1.4 Findings

This review explored the experiences of seeking support from mental health services and the barriers reported by South Asian service users. Following the meta-synthesis, three themes emerged: *Distanced from services*, *Dilemma of trust* and *Threat to cultural identity* (Table 5).

Table 5. Themes and concepts.

Themes	Concepts
<b>Distanced from services</b>	Outside of awareness
	Outside of cultural norms
<b>Dilemma of trust</b>	Cannot trust non-Asian professionals
	Cannot trust Asian professionals
<b>Threat to cultural identity</b>	Lack of cultural sensitivity
	Lack of collaborative care

The line of argument synthesis indicated that service users were positioned at a distance from being able to access services, either due to a lack of awareness of their availability and remit or due to cultural norms which discouraged them from seeking help outside the family. Service users were stuck in a dilemma of mistrusting professionals from different ethnic backgrounds, due to fears of personal and interpersonal invalidation. Furthermore, they constructed their cultural identity using a set of important values, which were neglected in their interaction with mental health services. Service users appeared to engage in an ongoing evaluation of the potential benefits of accessing services against the risks of threat to their personal and cultural identity. Many encountered experiences of limited collaboration and negation of their cultural identity when accessing services, which appeared to confirm their suspicions of fear or mistrust, and reinforced their distanced position from services.

These themes and concepts are not necessarily sequential, and may not apply to all South Asian service users. Rather, they represent the experiences reported by study participants and the choices that appeared necessary to consider and negotiate, in order to access a service that fully and effectively met their needs. Table 6 shows how the six concepts were derived and distributed across the fifteen studies. Each theme is then described together with the relevant concepts. Quotes are included from studies to illustrate the concepts.

Table 6. Distribution of themes and concepts across the identified studies.

Paper	Distanced from services		Dilemma of trust		Threat to cultural identity	
	Outside of awareness	Outside of cultural norms	Cannot trust Asian professionals	Cannot trust non-Asian professionals	Lack of cultural sensitivity	Lack of collaborative care
Bhui, Chandran & Sathyamoorthy (2002)	✓			✓	✓	✓
Bowl (2007)	✓	✓		✓	✓	✓
Chew-Graham et al. (2002)	✓	✓	✓	✓	✓	
Gilbert, Gilbert & Sanghera (2004)	✓	✓	✓	✓	✓	
Hussain & Cochrane (2002)			✓	✓	✓	✓
Hussain & Cochrane (2003)			✓		✓	
Hussain (2006)					✓	
Kai & Hedges (1999)	✓	✓		✓	✓	✓
Mahmood (2012)	✓	✓			✓	
Moller, Burgess & Jogiyat (2016)	✓	✓	✓	✓	✓	✓
Patel (2016)	✓	✓	✓	✓	✓	✓
Ruprai (2016)	✓	✓		✓	✓	
Sudan (2004)	✓	✓			✓	✓
Thompson (2010)	✓	✓	✓	✓	✓	✓
Wood (2011)		✓	✓	✓	✓	

### 1.4.1 Theme 1: Distanced from services

Service users were positioned at a distance from being able to access services for mental health difficulties. This was due to a lack of awareness of the availability or remit of services, or as a result of cultural norms and practices which discouraged them from seeking help outside the family or community. The two concepts within this theme represent these barriers including: *Outside of awareness* and *Outside of cultural norms*.

#### 1.4.1.1 Concept 1: *Outside of awareness*

Eleven of the fifteen studies reported a lack of awareness or knowledge of mental health services as a barrier to seeking help. Service users were unaware of any local community services except their GP (Kai & Hedges, 1999) and were unaware of alternatives to biomedical treatments offered by services (Ruprai, 2016). Many spoke about their confusion or uncertainty regarding the role of mental health professionals, illustrated by one participant in Mahmood's study (2012, p. 62):

*"Well, I don't know a lot about it. I know that the psychiatrist and the psychologist are the people who are dealing with those things I mean well broadly speaking, I don't have any idea of how these people work and I've never been in any organisation like that before."*

Some questioned, *"how do you find out about these services?"* (Gilbert et al., 2004, p. 124), whilst others relied on sources including the media for information (Ruprai, 2016).

Approaching mental health services was often not considered necessary, as service users felt their families and communities already provided a useful support system (Patel, 2016). The family was viewed by service users as their main source of support since there were strong intergenerational expectations about duty and responsibility to care for people with problems (Ruprai, 2016). The wider community was positioned as being protective of its

members, and assumed a collective responsibility to support one another in times of distress, as described by one male service user:

*“If you have a network of people, who are saying to you ‘we understand that you have a problem, but we are going to do whatever it takes in order to help you’. That’s when you know that you can get through it, because you’re not alone anymore. That vulnerability kind of shifts, because you’re not reliant on just yourself to get over it, and you know you have the support of everyone else.” (Patel, 2016, p. 50)*

Additionally, some service users viewed themselves as already having good psychological wellbeing, drawing on inner resources to cope with difficulties, including self-reliance and emotional control (Mahmood, 2012; Ruprai, 2016). This was attributed to values imbibed from family during childhood, or from spiritual and religious teachings. Therefore when the use of services was suggested, some service users denied their applicability, saying *“why I need because I know myself what I’m doing”* (Mahmood, 2012, p. 67).

#### 1.4.1.2 Concept 2: *Outside of cultural norms*

When service users were aware of available services, studies showed that they were reluctant to seek help for fear of potential negative consequences. This included a fear of being labelled as someone with mental health problems, due to the *“stigma attached to being a bit crazy or depressed”* or *“the impression of people who go to counselling”* (Moller, Burgess & Jogiyat, 2016, p. 207).

Studies reported that sensitive information was often privileged to the immediate family in Asian communities. Participants wondered *“why would you want to wash your dirty laundry in public?”* (Patel, 2016, p. 44), and therefore did not share their problems with others who were less well known and less trustworthy. Women stated that speaking openly about their feelings, especially in public, was frowned upon (Bowl, 2007), whereas men

were expected to uphold a strong demeanour and inhibit open displays of emotion, conforming to traditional constructs of masculinity (Mahmood, 2012). The notion of seeking help from a source outside the family was therefore regarded as not conforming to Asian cultural values and counter to family expectations (Wood, 2011).

Given the importance of the family unit, perceived shame and stigma naturally extended beyond the service user to their families, and had the potential to impact on family honour or reputation, or izzat. The consequences of this included damage to marriage prospects, negation of the family's success, rejection or disownment, and being shunned by the Asian community (Moller, Burgess & Jogiyat, 2016; Patel, 2016). In order to avoid this and protect izzat, mental health problems were confined within the family unit (Chew-Graham et al., 2002). This led to some service users feeling *"trapped because she is bound by all the obligations of the family, to her responsibilities as a mother, as a wife, to society, to izzat, everything"* (Gilbert et al. 2004, p. 120).

#### **1.4.2 Theme 2: Dilemma of trust**

This theme represents the feelings of mistrust and fear that dominated service users' perceptions and experiences of interacting with mental health services. Trust was reported as a fundamental requirement, since *"people only seek help from people they trust"* (Patel, 2016, p. 44). It contains two concepts: *Cannot trust non-Asian professionals* and *Cannot trust Asian professionals*.

##### **1.4.2.1 Concept 1: *Cannot trust non-Asian professionals***

Across the reviewed studies, service users overwhelmingly reported a fear of being misjudged by non-Asian professionals. This was related to a view that White professionals

were ‘culturally ignorant’ and are *“incapable of relating to a South Asian”* (Moller, Burgess & Jogiyat, 2016, p. 205). Service users expressed concerns regarding how professionals would respond to them if they sought help. For example, judging them as an ‘Asian’ woman, making naive statements which were actually racist or fixed on stereotypes, or offering simplistic sweeping solutions like ‘leaving the family’ without understanding the complexities of their experience (Chew-Graham et al., 2002). This ‘cultural incongruence’ led to some service users feeling uncomfortable and disengaging from services (Wood, 2011).

Conversely, Asian professionals were perceived as sharing cultural understanding and values. This meant a better grasp of their difficulties and contextual situation, ease of sharing and talking, and therefore a better understanding of them as an individual (Moller, Burgess & Jogiyat, 2016). Despite South Asians coming from diverse linguistic, religious and national backgrounds, one service user reported significant cultural similarities which enabled him to trust Asian professionals with information that *“he would not share with others”*, especially in settings where he was the minority (Bowl, 2007, p. 11).

#### 1.4.2.2 Concept 2: *Cannot trust Asian professionals*

Despite Asian professionals potentially being more understanding of cultural issues, eight studies reported that service users were concerned about seeking help from them. These concerns were predominantly about confidentiality not being respected, which was associated with a view that Asian professionals *“gossip and judge regardless of what they may say to their bosses”* (Moller, Burgess & Jogiyat, 2016, p. 206). Rumours were a threat to the family’s izzat since the Asian community was regarded as close-knit with a well-established ‘community grapevine’ (Chew-Graham et al., 2002, p. 342), in which *“every movement we make is scrutinised”* (Wood, 2011, p. 55). This meant that it would be

impossible to have *“full privacy when speaking to a counsellor”* (Moller, Burgess & Jogiyat, 2016, p. 206). One service user described feeling judged about her behaviour, which led her to censor what she shared (Wood, 2011).

Some service users also reported experiences of professionals breaching confidentiality. Examples were given of professionals informing family members of their concerns about the service user (Gilbert et al., 2004), or disclosing their whereabouts after they fled domestic violence in the family (Chew-Graham et al., 2002). These experiences led to suspicions and huge mistrust of all statutory services, resulting in service users only considering help-seeking as a last resort in desperate circumstances.

On the other hand, non-Asian professionals were perceived by South Asian service users as non-judgmental and objective, as described by one service user:

*“I would prefer a white person, because she is distant from the whole cultural situation, so she is more likely to be neutral.”* (Moller et al. 2016, p. 206)

However, this preference also depended on the nature of the situation, as *“if it was something that was stigmatised in my culture then I would definitely go to a white person”* (Moller, Burgess & Jogiyat, 2016, p. 207). These mixed experiences led to a dilemma, whereby service users believed that they could not trust any professionals, Asian or otherwise. One service user expanded on this:

*“You see no matter which GP you go to, a European one is going to come with his European values, and then he will try and be more objective but he will still be coming from that angle, and you know he will derive his cultural values from somewhere else, whereas an Asian GP will get them from somewhere else, so you are not going to get an objective point of view from anywhere really.”* (Gilbert et al., 2004, p. 125)



### 1.4.3 Theme 3: Threat to cultural identity

Service users experienced help-seeking as bringing them into conflict with their needs, expectations and values, which impacted on their sense of self. This related to their experiences as an individual seeking help at a time of distress and based on their cultural identity as a South Asian adult in the UK. This theme contains two concepts: *Lack of cultural sensitivity* and *Lack of collaborative care*.

#### 1.4.3.1 Concept 1: *Lack of cultural sensitivity*

This concept highlights the disparities between the cultural needs of South Asian service users and the way in which professionals delivered services. Service users felt professionals were not interested in their cultural identity since questions were only asked about their ‘illness’, not the South Asian identity behind it (Sudan, 2004). Salient information was not recognised, including the historical, political, social and cultural context of their lives, as opposed to knowledge about customs and rituals (Hussain & Cochrane, 2002).

Language was viewed as intricately linked to culture, whereby service users referred to language as a reflection of their cultural and ethnic identity (Sudan, 2004). It was considered crucial for accurate knowledge and communication, leading to professionals missing information or misunderstanding the service user (Bowl, 2007). One participant stated that:

*“We have the words in our language, but they might not be translatable. You know they might come out harsher or softer, than they're trying to portray. So you would – like you have with any translation, you can't use word for word in most cases. You would have to – you'd have alternatives and it might not be as it's supposed to come out, or exactly what the person is feeling.”*  
(Patel, 2016, p. 56)

In response to this need, services often did not have interpreters arranged or provided. Professionals made assumptions about English proficiency and continued assessments without offering interpreters (Bhui, Chandran & Sathyamoorthy, 2002). This created distress and alienation for service users, preventing them from fully being themselves and having to rely on support or advocacy from others. Some service users arranged for family members to accompany them, although reluctantly as *“it isn’t right that you have to bring someone”* (Bowl, 2007, p. 9). This also inhibited them from speaking out about distress that may have involved the family (Gilbert et al., 2004).

Another important cultural aspect was their understanding of emotional distress. Service users largely positioned emotional distress as being related to social disadvantage and stressful situations. Some believed that their distress was a normal reaction to their situation, suggesting that they were not *“ill”* or in need of coping strategies (Hussain & Cochrane, 2003, p. 35). One service user emphasised the differences between Eastern and Western conceptions of distress:

*“It’s old fashioned to be honest, to think that physical and mental are different. Because what is happening physically in your body, is affecting your mind, so no they are not two separate things. So I think doctors need to be mindful of that. The Western medicine needs to change, accepting that all the things are linked.”* (Patel, 2016, p. 36)

These differences in understanding led to concerns about medication as a first-line treatment for emotional distress. Service users expressed concerns about the side effects and long-term impact; *“it’s not good to take this medication for long...because it’s not good for you”* (Hussain & Cochrane, 2003, p. 303), so many regarded medication as a last resort.

Consequently, seeking help from doctors was seen as one of many paths to a possible solution, with limited ability to effect real change (Hussain & Cochrane, 2002). Many service users felt that *“doctors only give medical help...they do not have knowledge of problems*

*that worry people*” (Kai & Hedges, p. 13); their role was seen as limited to signposting and prescribing as they only treated the biomedical symptoms and not the underlying social causes.

Many service users described the importance of religion and faith in their conceptualisation of distress. This was a protective factor, conferring mental strength, motivation and comfort (Thompson, 2010), which was central to their ability to manage difficulties. Religion influenced the attitudes and beliefs around distress and help-seeking, as well as the use and experience of statutory services (Hussain, 2006). For example, advice from spiritual healers was viewed as more credible than that of professionals, and service users often sought spiritual treatment alongside medical treatment (Hussain & Cochrane, 2002). Accounting for religion and understanding spiritual factors was considered crucial and at times privileged over shared ethnicity (Moller, Burgess & Jogiyat, 2016).

However, religion in healthcare was experienced as *“knowledge first and faith last”* (Thompson, 2010, p. 70). Service users felt that these needs were rarely acknowledged if at all, and felt that they could only volunteer this information if professionals appeared to accept spiritual explanations themselves. Furthermore, they reported that non-Asian professionals tended to pathologise these beliefs, as described by one participant:

*“It’s one thing to have knowledge about something but it’s another to live it right? My counsellor said he didn’t understand some of the things we did and why we did them – that worried me...after a while I stopped going.”* (Hussain & Cochrane, 2002, p. 304)

#### 1.4.3.2 Concept 2: *Lack of collaborative care*

Service users described experiences of feeling disempowered and dehumanised by services. Some reported that professionals often would not share pertinent information with them,

such as their role, understanding of the problem, what to expect and the outcome of the assessment. GPs were seen to position themselves as experts, forcing service users and telling them what was required (Kai & Hedges, 1999). Others were offered limited choices regarding their preferences, including gender or ethnicity of professional, or treatment options, and felt that they were viewed as a diagnosis or a “*statistic*” (Ruprai, 2016, p. 76). One service user expressed dissatisfaction with this lack of collaborative care from professionals:

*“They don’t sit you down and discuss the background and their thoughts on the illness and its causes and ask questions about different explanations—you know, all the things that help you arrive at an accurate diagnosis and help you work with the problem. It’s common knowledge that if two people present with similar symptoms, it doesn’t mean it’s the same illness...it’s about asking the right questions.”* (Hussain & Cochrane, 2002, p. 301)

Furthermore, service users often valued the presence of family members for reassurance and support (Bhui, Chandran & Sathyamoorthy, 2002). One service user talked about the importance of involving the family in mental health care:

*“It’s not an individualistic thing...within a South Asian culture...families don’t take decisions as individuals, you take major decisions together...the family would want to be included.”* (Patel, 2016, p. 55)

Despite this, service users felt that statutory services did not appreciate the importance of the family unit, ignored them regarding key decision-making processes, and provided them with little support. This was deemed especially problematic for families who perceived themselves as having little knowledge or experience of mental health, and those who were interested in providing support to the service user but were not given any opportunities to learn how to do this (Bowl, 2007; Sudan, 2004). Additionally, professionals rarely facilitated collaboration to improve the quality of care, instead involving family to mitigate the need for an interpreter (Hussain & Cochrane, 2002).

## 1.5 Discussion

This systematic review synthesised qualitative evidence on the experiences of seeking support for mental health problems in primary care settings, and the barriers reported by South Asian service users. Fifteen studies met the inclusion criteria and were analysed in line with the principles of meta-ethnography. Three themes emerged: *Distanced from services*, *Dilemma of trust* and *Threat to cultural identity*.

A lack of awareness of mental health service provision was an initial barrier to accessing services for South Asian service users. Cultural norms and practices also influenced their decision to access services, where fear of stigma, shame, and the impact on family izzat were valid concerns. This is supported by findings from previous reviews (Selkirk, Quayle & Rothwell, 2014) and a large meta-synthesis of data from marginalised groups, where the communicated availability of services was the main facilitator for access to primary mental health care, hindered by lack of effective communication from services and multiple forms of stigma within communities (Kovandžić et al., 2011). Other research has found that the personal costs associated with engaging with services may be greater for BAME groups, where individual resources can be limited and the stigma attached to mental health is high (Lamb, Bower, Rogers, Dowrick & Gask, 2012).

Furthermore, language differences were reported to be a crucial barrier. Language is necessary to articulate needs, but can also characterise cultural communication styles and behavioural norms. Service users reported interpreters not being arranged or provided, which has implications for the quality of healthcare received, since service users with poor English language proficiency report poorer satisfaction with healthcare consultations (Brodie, Abel & Burt, 2016). Language differences can perpetuate misunderstandings

regarding how the healthcare system works and what it can and cannot provide (Murray & Buller, 2007; Saha, Fernandez & Perez-Stable, 2007), but also result in limited knowledge about rights, and slower progression from diagnosis to treatment (Chew-Graham et al., 2002; Hussain & Cochrane, 2002; Hussain & Cochrane, 2003). Given that these barriers distance service users from adequately engaging with mental health services, they are often described as 'hard-to-reach' (Salway et al., 2011). However, Lightbody (2017) argues that BAME communities are not hard-to-reach, but 'easy-to-ignore' due to the complexity of their situation and a lack of understanding from statutory organisations.

Some researchers propose that improving the mental health literacy of South Asian communities could improve attitudes towards help-seeking (Protheroe et al., 2009). Although this may alleviate barriers that are mainly cognitive or informational, determinants of help-seeking included social, interpersonal, and affective factors for South Asian service users (Kirmayer, 2015). The Cultural Determinants of Help-Seeking model supports that health promotion must attend to the social norms and values for a given cultural group to be meaningful and effective (Saint Arnault, 2009). Contrary to this, the literacy approach assumes that adopting a Western understanding of mental health problems will lead to appropriate mental health services for all populations. However, applying standard Western healthcare models in a 'colour-blind' manner can risk alienating BAME groups by providing interventions that are culturally incongruent, and can be ineffective and potentially harmful. It may also perpetuate colonial power dynamics, reinforcing cultural mistrust of services for South Asian service users (Fernando & Keating, 2008; Hussain, 2006).

A dilemma of trust was a key determinant of decisions to access primary mental health care. Service users were stuck between trusting Asian professionals or non-Asian

professionals, based on legitimate concerns regarding the subsequent validation, empathy and privacy each might provide. This raises questions about the utility of ethnic-matching, which proposes that matching the ethnicity of service users to professionals facilitates service delivery (Bhui, Bhugra & McKenzie, 2008). Ethnic-matching is usually approximate and can prevent exploration of other aspects of cultural identity that may be more relevant for service users (Kirmayer & Gómez-Carrillo, 2018). What appeared more important for South Asian service users was a commitment to confidentiality, acknowledgement of their cultural identity, and a genuine interest to attend to their conceptualisation of distress and religious/spiritual values.

Service users' mistrust of non-Asian professionals reflected the concept of 'cultural mistrust' (Whaley, 2001). This concept posits that Black groups have developed a mistrust of White service providers as a result of their historical and contemporary experiences with racism and colonial oppression (Keating & Robertson, 2004; Brooks & Hopkins, 2017). This mistrust also appeared to apply to South Asian service users who expressed 'healthy cultural suspicions' that their "psychological distress may be misunderstood, misconstrued and/or pathologised, and their own beliefs severely compromised or at worst undermined" (Williams et al., 2006, p. 329). This is a novel association for this group, and may partly explain their limited engagement and reluctance to engage with mental health services.

South Asian service users reported professionals exerting control over decision-making processes, stereotyping them on the basis of cultural norms, and overlooking fundamental beliefs, such as their religious values. These experiences created a power imbalance, where service users were unable to influence their care in any meaningful way or assert their personal or cultural identity. Previous research discovered that mental health

professionals, including GPs and consultant psychiatrists, held stereotypes regarding South Asian cultures as repressive, patriarchal, and inferior to a Western cultural ideal, and therefore pathologised the culture as predisposing towards emotional distress (Burr, 2002). Furthermore, doctors delivered less competent clinical performance to BAME groups, due to presumptions about the intelligence and expectations of these groups (Cooper & Roter, 2003). Coyle (1999) posits that threats of being stereotyped, disempowered and devalued, can impact on service users' sense of self, especially impacting on women and those from BAME backgrounds. South Asian service users were therefore understandably reluctant to seek help from services which posed a threat to their autonomy, personal values, and understanding of mental health (Lamb et al., 2012).

It has been proposed that 'cultural safety' needs to be promoted in order to address the observed power imbalances and cultural mistrust between BAME groups and healthcare providers (Ramsden, 2002). Originally developed in relation to the significant health disparities experienced by Maori service users in New Zealand, cultural safety aims to recognise the social, economic and political position of marginalised groups within society, and promote equitable partnerships by challenging healthcare providers to "reflect on their own positions of power and privilege within society and how this influences their usually unconscious assumptions and comparisons about others" (Gerlach, 2012, p. 153). In this approach, the definition of culturally-safe practice and its success is determined by the recipient of healthcare, rather than the provider (Brascoupé & Waters, 2009). This would transfer the power of the interaction from professionals to South Asian service users, enabling them to have the power to comment on their care and be involved in positive change (Gerlach, 2012).



Given the multiple existing barriers to accessing primary mental health care, it is suggested that South Asian service users perceive these services as highly impermeable (Dixon-Woods et al., 2005). This supports the candidacy model of access, which has been applied in other contexts to account for barriers to care in 'hard-to-reach' groups (Koehn, 2009; Kovandžić et al., 2011; Lamb et al., 2012). The review also provides evidence to support the suggestion that cultural dissonance creates low permeability; South Asian service users construed and presented their emotional distress differently from the imagined 'ideal' user of mental health services, leading to a dissonance between their expectations from services with the intended use of services (Hussain, 2006; Dixon-Woods et al., 2005).

### **1.5.1 Implications for policy and clinical practice**

This review argues that the availability of services needs to be promoted to the South Asian community, and the visibility of professionals increased. Services need to consider how information is best communicated to South Asian service users, and by whom. It is suggested that 'cultural brokers' from the South Asian community may be better placed to share information (Kirmayer & Gómez-Carrillo, 2018). Service user groups could also be established to inform service planning and development locally and nationally, ensuring that change remains on the political agenda (Fernando & Keating, 2008).

Services need to consider ways in which to increase permeability and establish more equality in the power dynamics of consultation (Bhui, Chandran & Sathymoorthy, 2002). One way this could be demonstrated is by offering a choice of professional, based on the service users' preferences towards ethnicity, gender or language. Another way is to improve the access and availability of professional interpreters and refining interpreting techniques (Brodie, Abel & Burt, 2016). All service providers must take responsibility to increase their knowledge and awareness of the cultural values and norms deemed

important for the South Asian service users they serve, as well as the socio-political context affecting their lives (Sue & Sue, 2012). Clinical practice must be delivered in a way that achieves cultural safety and congruence (Brascoupé & Waters, 2009; Kirmayer & Gómez-Carrillo, 2018). Greater collaboration between statutory services and local communities may further assist in redressing the power imbalance between professionals and service users, by building trust and mutually respectful partnerships (Bowl, 2007).

Professional training across disciplines should acknowledge cross-cultural variations as fundamental to understanding what is considered valid or ‘normal’ expressions of distress and help-seeking (Barn & Sidhu, 2005). Although Delivering Race Equality in Mental Health Care (DoH, 2005) has stated a requirement for all mental health practitioners to receive training in race equality and culturally sensitive care, this has not yet led to marked changes in clinical practice in the UK. Existing literature suggests that this reflects the need for a change in clinician’s self-awareness and attitudes towards patients from diverse ethnic backgrounds, not a lack of cultural knowledge (Tervalon & Murray-Garcia, 1998). Therefore, rather than achieving the detached outcome of ‘cultural competence’, the ongoing process of ‘cultural humility’ needs to be stimulated.

Cultural humility refers to the flexibility and humility of professionals to let go of the false sense of security that stereotyping brings, to admit to not knowing when this is the case, and to reassess the needs and experiences of each patient based on their unique cultural context (Tervalon & Murray-Garcia, 1998). There must be a lifelong commitment to the process of self-reflection and self-evaluation, in which curiosity, interest, and respect are maintained for the beliefs, values and cultural norms deemed important for South Asian service users, and these are considered integral to their mental health care (NIMHE, 2004).

### **1.5.2 Strengths and limitations of the review**

This literature review is the first attempt to examine the utilisation of primary mental health care by South Asian service users in the UK, using a systematic search strategy and meta-ethnography approach. By employing a comprehensive search to identify relevant studies, this review followed a more transparent and reproducible process than using a search with purposive sampling, which would have been likely to omit some studies (Ring et al., 2010).

Analysing the research using the principles of meta-ethnography enabled a detailed and deeper insight into the perceptions and experiences of services users. However, it is important to recognise that syntheses of this nature are distanced from the lived experiences of the participants they represent since the studies themselves have interpreted the participants' data (Sandelowski & Barroso, 2007).

It is acknowledged that there is a 'category fallacy' when identifying South Asians as a homogenous group since there is a wide range of religious, linguistic, and cultural diversity in migrants who originate from countries on the Indian sub-continent (Bhopal, 1997). However, this review is the first attempt to investigate the views of this group separately from other ethnic groups and service providers, giving voice to their unique combined experiences.

The review included studies with first and second-generation adults in their samples. This allowed for varied perspectives to be considered, but may have obscured important differences in help-seeking arising from acculturation (Pilkington et al., 2012). Since most studies included both first and second-generation immigrants in their samples, it was

difficult to focus on either generation. Instead, children and adolescents were excluded based on age.

### **1.5.3 Recommendations for future research**

Given the novel finding of mistrust of statutory services, future research could explore this association to understand the potential influence of cultural mistrust in South Asian communities, and to identify the practices that would facilitate in building trust. The relationship between personal and cultural identity and help-seeking could also be explored, to clarify the processes that enable service users to retain their sense of self while seeking help for emotional distress, and possible service responses that could facilitate this.

It was noted that participants in the fifteen studies may have had varied experiences as a result of their identity characteristics, e.g. first and generation immigrants, ‘potential’ and ‘actual’ service users, and different ethnic groups within the ‘South Asian’ ethnic category. It may be useful for future studies to investigate the experiences of these groups separately, in order to further tailor service responses. Additionally, the quality and reporting of research in this area could be improved through researchers providing adequate information about the method and process of qualitative analysis, and the reflexive steps taken to address potential biases.

More research is needed to understand cultural mistrust in the mental health context, and how this interacts with access and permeability. Attending to the views of clinicians could illuminate reciprocal influences on help-seeking and permeability, and consider strategies to improve these from their perspective. The perceptions of South Asian service users with positive experiences of help-seeking could further shed light on approaches to address the identified barriers and recognise good practice.

## **1.6 Conclusion**

This systematic review utilised a meta-ethnographic approach to investigate the experiences of help-seeking and perceived barriers to accessing mental health services, as reported by South Asian service users in the UK.

South Asian service users reported not having adequate information about what services can provide, and believed that statutory services could not offer support that is empowering or culturally-sensitive. From their experiences of seeking help, they affirmed that healthcare professionals disregard their cultural needs and show limited interest or collaboration to account for these. This brought them into conflict with their personal and cultural identity, inadvertently perpetuating feelings of mistrust, disempowerment and alienation.

If South Asian service users are to receive an equitable mental health service, culturally-congruent methods of assessment and intervention are essential. It must be recognised that a radical paradigm shift is necessary for mental health care to become culturally safe and meet the needs of a diverse and multi-cultural society. Greater collaboration between service providers and South Asian communities could facilitate trust through familiarity and positive relationships.

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## **CHAPTER 2 – EMPIRICAL PAPER**

### **Exploring the lived experiences of South Asian women with medically unexplained symptoms: an interpretative phenomenological analysis**

This paper has been prepared for submission to *Qualitative Health Research*  
(See Appendix S for Author Guidelines)

Original word count (excluding abstract, tables and references): 7,992

## 2.1 Abstract

Medically unexplained symptoms (MUS) are persistent bodily symptoms that cannot be explained by adequate medical examination and can cause significant distress and impaired functioning. Cross-cultural variations indicate that South Asian women with MUS utilise healthcare services more than other ethnic groups in the United Kingdom (UK), although few studies have explored their lived experiences. Interpretative phenomenological analysis was used to explore six South Asian women's experiences of living with MUS and seeking support. Three super-ordinate themes emerged: *Multiple assaults on the self*, *Suffering in silence* and *Reconstructing the self*. It is argued that South Asian women with MUS are marginalised at multiple levels in their lives, through their needs being ignored and their emotional distress being silenced and medicalised. The research recommends that services implement a more culturally-sensitive and person-centred approach, and acknowledge the impact of traumatic experiences on the expression and experience of MUS in South Asian women.

## **2.2 Introduction**

### **2.2.1 Medically unexplained symptoms in context**

This study aimed to explore the lived experiences of South Asian women with medically unexplained symptoms (MUS). MUS is a term commonly used to describe persistent bodily symptoms which cannot be explained by adequate medical examination (Chew-Graham & Heyland, 2017). Symptoms can present as pain in different parts of the body, functional disturbance of organ systems, or complaints of fatigue or exhaustion, resulting in a range of symptoms such as musculoskeletal pain, persistent headache or migraine, chest pain, abdominal pain or discomfort, heart palpitations and chronic fatigue. MUS may be caused by physiological disturbance or pathological conditions which have not yet been diagnosed, although only 4-10% of people with MUS have an organic explanation for their symptoms (Chitnis, Dowrick, Byng, Turner & Shiers, 2011).

Typically, MUS are long-lasting and can cause significant distress and impaired functioning day-to-day, with an increased likelihood of co-morbid mental health problems in service users with multiple physical symptoms, which can further exacerbate symptoms (Chew-Graham & Heyland, 2017). Research and clinical practice regarding MUS has traditionally been confined to examining single organ systems, giving rise to diagnoses such as chronic pain or irritable bowel syndrome. However, substantial evidence suggests that the differentiation of MUS into discrete diagnostic conditions is not clinically relevant and reflects the inclination of medical specialists to focus on symptoms relevant to their speciality, rather than any real differences between patients (Guo, Kleinstäuber, Johnson & Sundram, 2019; Wessely, Nimnuan & Sharpe, 1999).

Given this overlap in symptoms, there is often no clear referral pathway for people with MUS. They are associated with an increased presentation to primary and secondary care, accounting for up to 20% of General Practitioner (GP) consultations and 20-50% of medical outpatient referrals across a range of specialities such as rheumatology, gastroenterology, cardiology and neurology (Chitnis et al., 2011). This contributes to long waiting lists and enormous healthcare costs; for instance, annual healthcare costs of MUS exceed £3.1 billion in the United Kingdom (UK), with total societal costs estimated at £18 billion (Bermingham et al. 2010).

The terminology used to describe these symptoms has been subject to considerable debate. Concepts including ‘functional somatic symptoms’, ‘persistent physical symptoms’ and ‘bodily distress syndrome’ have been proposed as alternatives to MUS, each with its own advantages and limitations (Henningesen, Fink, Hausteiner-Wiehle & Rief, 2011). This contention can involve an additional burden of suffering for people with MUS, due to profound uncertainty, lack of recognition, social stigma and the potential denial of access to benefits and services (Greco, 2017). The term MUS is used in this article as it acknowledges the limited effectiveness of medical treatment for these symptoms and has been widely used by researchers and policymakers to date (Chew-Graham & Heyland, 2017).

### **2.2.2 Somatisation and cultural idioms of distress**

Existing literature on the treatment of MUS suggests that these difficulties are caused, maintained, or exacerbated by emotional and psychological factors (Edwards, Stern, Clarke, Ivbijaro & Kasney, 2010). The term ‘somatisation’ is often used to describe this association, whereby emotional or social distress is naturally embodied and expressed through bodily complaints (Burr & Chapman, 2004). Somatisation is experienced by most



people at some point in their lives, e.g. vomiting due to anxiety, or experiencing a headache due to stress; instances that are situational and temporary. However, somatisation can be regarded as a clinical issue, and may be labelled as MUS, when physical symptoms cause prolonged and severe distress, typically when they persist for over three months (Chitnis et al., 2011).

‘Central sensitisation’ has been proposed as the main aetiological mechanism, where MUS are regulated by a highly reactive state of the central nervous system (Guo, Kleinstäuber, Johnson & Sundram, 2019; Russell, Abbass, Allder & Neborsky, 2017). The ways in which service users might present with such symptoms is influenced by a number of factors, including their perceptions and attribution of distress, and evaluation of what is appropriate to disclose. Acknowledgement of distress may be hidden for fear of stigmatisation, whilst somatic symptoms may be viewed as more socially acceptable or amenable to medical treatment (Rastogi et al., 2014).

These dynamics are further coloured by cultural factors related to gender and ethnicity. For example, figures suggest that women are two times more likely to consult their GP about MUS than men (Steinbrecher et al., 2011). This could be attributed to the idea that women have greater bodily awareness, or that their emotional expression and symptom reporting is perceived as more socially acceptable, meaning they are more likely to seek help for MUS than men (Bendelow, 1993; Mobini, 2015). Additionally, Johnson (2008) argues that women are more commonly exposed to adverse life events such as abuse, neglect, and strained gender role expectations. Such experiences are known to have a detrimental impact on a person’s sense of self by shattering existential foundations (Thompson & Walsh, 2010). There is now consistent evidence demonstrating that traumatic life events such as childhood and/or adult abuse (emotional, physical, or

sexual), family dysfunction and exposure to war increase the likelihood of developing MUS (Afari et al., 2014; Yavne et al., 2018), perhaps through the impact of such events on central sensitisation (van der Kolk, 2014).

Research has demonstrated that somatisation is universal and common across ethno-cultural groups, and reveals the oldest and most common expression and clinical presentation of emotional distress worldwide (Hausteiner-Wiehle, Schneider, Lee, Sumathipala & Creed, 2011). In comparison 'psychologisation', or the emphasis on explicit dialogue about emotions and mental states, appears to be the more recent phenomenon, tending to occur in developed countries which prioritise individualistic explanations for distress (Goldberg & Bridges, 1988; White, 1982). In this context, somatisation may reflect the mind-body dualism inherent in a Western cultural ideology of health (Greco, 2017). Therefore, rather than the presence of MUS, it is the prevalence, symptoms and conceptualisations of MUS that appear to vary between ethno-cultural groups (Guo, Kleinstäuber, Johnson & Sundram, 2019).

In the UK, quantitative evidence has repeatedly found higher rates of GP utilisation in South Asian groups with MUS compared to other ethnic groups with MUS, even after attempts are made to adjust for need or socioeconomic status (Smaje & Le Grand, 1997; Sutton et al., 2002). This difference has been commonly explained by the notion that South Asian service users hold specific 'cultural idioms of distress' which influence the ways in which emotional distress is construed and managed. This can include a strong tradition of mind-body holism, culturally-sanctioned values regarding emotional expression and stigma around mental health (Grover & Ghosh, 2014; Maffini & Wong, 2014). It has been suggested that these factors are often neglected or ignored in healthcare consultations, leading to miscommunication and tension in the patient-doctor relationship (Kirmayer &

Sartorius, 2007). Indeed, GPs often express frustration in dealing with this group due to the frequency of their presentation to primary care (Patel et al., 2009; Closs, Edwards, Swift & Briggs, 2013).

Since these cultural idioms run counter to Western cultural norms surrounding psychologisation, they may lead South Asian service users to be labelled as not 'psychologically-minded' (Kirmayer, Dao & Smith, 1998). However, it has been argued that these explanations are untested and require more research, to reduce the perpetuation of faulty assumptions and stereotypes attributed to South Asian groups (Phillips & Lauterbach, 2017). It, therefore, remains unclear whether different rates of healthcare utilisation are influenced by differences in morbidity, help-seeking behaviours, socio-cultural differences, or poorer quality consultations that lead to repeated use (Dixon-Woods et al., 2005). Although there are multiple possible intersecting explanations for the higher levels of GP utilisation among South Asian groups with MUS compared to other ethnic groups with MUS, limited research has investigated service users' experiences of living with MUS and seeking help from health services in the UK.

### **2.2.3 The experiences and views of South Asian service users with MUS**

The wider literature has shown that patients see their MUS as a reaction to, or an interpretation of, their situation in the world; what leads the patient to seek help is not so much the symptoms, but what the patient thinks about them (Butler, Evans, Greaves & Simpson, 2004). Qualitative approaches, therefore, have much to offer in better understanding the needs of South Asian service users with MUS, and some studies have started to employ qualitative methodologies to explore their experiences.

Rogers and Allison (2004) found South Asian service users described their bodily pain symptoms as an extension of broader personal and social concerns and did not recognise these concerns as 'depression', but rather as understandable responses to stressful life circumstances. Peacock (2008) also found that South Asian service users experienced a loss of their previous identity and considerable change in their social roles and relationships. Coping strategies included a range of medical and holistic treatments, and often involved help from family members.

These studies highlight that barriers to achieving appropriate healthcare can involve both patients and professionals. Bayliss et al. (2014) found that language differences disempowered South Asian service users from articulating their symptoms or understanding the GP during a consultation, while apparent racist or stereotypical views prevented GPs from fully engaging with and addressing their concerns. Negative experiences of consultation meant that South Asian service users chose not to see their GP, instead using traditional herbal remedies or consulting religious/spiritual healers (De Silva, Bayliss, Riste & Chew-Graham, 2013).

#### **2.2.4 Rationale for the current research**

Although previous research has explored the association between cultural factors and somatisation, they have predominantly been from the perspective of the healthcare system and mostly employed quantitative methodologies. The few qualitative studies focusing on the experiences of South Asian service users either combined their data with that of carers or healthcare professionals or included other ethnic groups in their samples. None looked specifically at the experiences of South Asian women, a group understood to utilise healthcare services more frequently.

This study, therefore, aimed to employ interpretative phenomenological analysis (IPA) to explore the unique lived experiences of South Asian women with MUS in the UK. These objectives are supported by the wider MUS literature, in which using qualitative methods to understand patients' cultural background, needs and perspectives, was considered the third most important topic globally in MUS research (Olde Hartman et al., 2008).

The principal research question is: How do South Asian women experience living with MUS? A number of secondary questions were also explored including:

- How do South Asian women understand and make sense of their MUS, and cope with them day-to-day?
- What experiences do South Asian women have of seeking help and/or support for their MUS?

## **2.3 Method**

### **2.3.1 Research Design**

A qualitative research design was chosen to meet the aims of the study, guided by the principles of interpretative phenomenological analysis (IPA). This approach aims to gain a detailed insight into how individuals make sense of their experiences, by examining their involvement in, and orientation towards, a particular phenomenon (Smith, Flowers & Larkin, 2009). It is 'idiographic' in that it is committed to understanding the individual within their particular circumstances and context, and 'phenomenological' in that it emphasises the individual's personal perception of the phenomenon of interest, rather than attempting to produce an objective statement of the event or process (Smith & Osborn, 2008). Additionally, IPA emphasises that the meanings an individual ascribes to a particular phenomenon can only be obtained through an interpretative process, known as 'hermeneutics'. The researcher plays an active role in analysing the data and making sense of the individual's lived experiences, through their own conceptions and experiences. This dynamic process gives rise to a 'double hermeneutic', wherein both the researcher and participant are simultaneously involved in reflecting on and interpreting a particular phenomenon (Smith, Flowers & Larkin, 2009). In order to facilitate this depth of understanding, the principles of IPA were applied to all stages of data collection and analysis.

## **2.3.2 Participants**

### *2.3.2.1 Recruitment*

A non-probability sampling design was employed in this study since the goal was not to represent the population or generalise the findings, but rather to understand how a group of South Asian women experienced living with and seeking help for MUS. A purposive sampling method was used in order to select a homogenous sample. This is vital for IPA research as it allows participants to share characteristics with one another and become closely defined in a way that renders the research question significant (Smith & Osborn, 2008).

Participants were recruited from two community teams working with patients with MUS in the Midlands. Both teams provided routine assessment and treatment for individuals reporting MUS. The researcher met with the teams to share study information and research posters, which were displayed in waiting rooms and clinic rooms (Appendix F). Professionals in the teams identified service users on their caseloads who met the inclusion criteria and shared study information with them.

### *2.3.2.2 Inclusion and Exclusion Criteria*

A number of inclusion and exclusion criteria were applied to maximise the homogeneity of the sample and minimise possible selection bias. To be eligible for the study, participants needed to meet all of the inclusion criteria (Table 7).

Table 7. Inclusion and exclusion criteria for participants.

	Inclusion criteria	Exclusion criteria
<b>Gender</b>	Female	Male
<b>Ethnicity</b>	South Asian ethnicity (Indian, Pakistani, Bangladeshi, Sri Lankan)	Ethnicities other than South Asian
<b>Age</b>	Adults (aged over 18 years)	Children or adolescents
<b>Language</b>	English or Gujarati	Languages other than English or Gujarati
<b>Type of physical symptoms</b>	<p><i>Physical symptoms including:</i>  pains in the muscles or joints, back pain, chest pain, heart palpitations, headaches, fatigue, dizziness, blurred vision, insomnia, nausea, bloating, constipation, diarrhoea, abdominal pain, shortness of breath/hyperventilation  AND/OR  <i>Functional conditions including:</i>  chronic widespread pain, chronic pelvic pain, chronic lower back pain, atypical/non-cardiac chest pain, irritable bowel syndrome, non-ulcer dyspepsia, chronic fatigue syndrome/myalgic encephalomyelitis, fibromyalgia, hyperventilation syndrome, tension headache, non-epileptic attack disorder/pseudo-epileptic seizure, atypical facial pain, multiple chemical sensitivity, functional dyspraxia</p>	N/A
<b>Explanation for physical symptoms</b>	Physical symptoms which have been medically investigated and no organic pathological mechanism has been identified, or are above and beyond those explained by a medical diagnosis	Physical symptoms which have not been medically investigated, are currently being medically investigated, or are adequately explained by an organic pathological mechanism or medical diagnosis
<b>Symptom duration</b>	3 > months	<3 months
<b>Capacity to consent</b>	Able to give valid informed consent to participate in the study	Unable to give valid informed consent e.g. due to severe mental health difficulties or cognitive impairment



Participants who self-identified as Indian, Bangladeshi, Pakistani or Sri Lankan were included; ethnic groups which come under the umbrella of 'South Asian'. Only women were included as it was anticipated that they would be utilising services more frequently than men, and would, therefore, be easier to recruit. Participants under the age of 18 years were excluded, as it was considered that adults may be more able to reflect on their cultural identity in relation to their symptoms. Since the researcher can speak Gujarati, and ethnic minority groups are often excluded from research due to the barriers present in accessibility and translation (Bhopal, 1997), participants who were comfortable speaking English or Gujarati were included in the study.

Participants were deemed as experiencing MUS if they reported persistent physical symptoms for at least three months, which were objectively verified as being medically unexplained by professionals with experience working with MUS. All participants recruited for the study reported chronic pain<sup>1</sup> and/or fibromyalgia<sup>2</sup> as their main diagnoses, which improved the homogeneity of the sample.

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<sup>1</sup> Chronic pain is a condition which persists for longer than expected, despite appropriate medical intervention. It can affect various bodily systems, including the central nervous system and musculoskeletal system.

<sup>2</sup> Fibromyalgia is a widespread pain condition which can affect multiple bodily systems, including the central nervous system, gastrointestinal and endocrine systems. A diagnosis is typically given by a rheumatologist when symptoms do not follow any pattern of inflammatory disease or musculoskeletal injury.

### 2.3.2.3 *Sample Characteristics*

Six participants were interviewed who met the inclusion criteria. This sample size was considered adequate to allow for sufficient in-depth engagement with the material presented by each participant, but also allow for meaningful examination of the similarities and differences between them (Smith & Osborn, 2008). Pseudonyms were assigned to each participant to protect their identities. Table 8 shows the demographics of the interviewed sample, and Table 9 details their symptoms and use of services.

Table 8. Participant demographics.

Pseudonym	Age range	Ethnic group	Place of birth	Years lived in the UK	Languages spoken	Religion
<b>Jyoti</b>	60-65	Indian	Gujarat, India	46	Gujarati, English, Hindi	Hinduism
<b>Champa</b>	50-55	Indian	Gujarat, India	30	Gujarati, English, Hindi	Hinduism
<b>Amna</b>	30-35	Indian	Mumbai, India	9	Hindi, Marathi, Urdu, English	Islam
<b>Nafisa</b>	50-55	Bangladeshi	Sylhet, Bangladesh	39	Bengali, Urdu, Hindi, Punjabi, English	Islam
<b>Sushila</b>	45-50	Indian	Maputo, Mozambique	21	Portuguese, Gujarati, English	Jainism
<b>Kiran</b>	35-40	Indian	England	37	English, Punjabi	Sikhism

Table 9. Participants' symptoms and use of services.

Pseudonym	Diagnoses	Somatic symptoms reported	Duration of symptoms (years)	Length of investigations (years)	Medical professionals /services	Mental health professionals /services
<b>Jyoti</b>	Fibromyalgia, chronic pain, anxiety, depression	Pains in the muscles, pains in the joints, pain in legs and arms, headaches, nausea, stammer	8	6	GP, Rheumatologist, Pain management	Psychiatrist, Mental Health Nurse, Clinical Psychologist, Counsellor
<b>Champa</b>	Fibromyalgia, chronic pain, cervical spondylosis, sciatica, depression	Pains in the muscles, pains in the joints, back pain, chest pain, headaches, fatigue, blurred vision, constipation, shortness of breath	5	3	GP, Rheumatologist, Pain management	Psychiatrist, Mental Health Nurse, Counsellor
<b>Amna</b>	Fibromyalgia	Pains in the muscles, pains in the joints, back pain, dizziness, blurred vision, insomnia, constipation, shortness of breath	3	1	GP, Rheumatologist, Podiatrist	Clinical Psychologist
<b>Nafisa</b>	Fibromyalgia, chronic pain	Pains in the muscles, pains in the joints, back pain, chest pain, headaches, fatigue, dizziness, blurred vision, insomnia, nausea, abdominal pain	30	24	GP, Rheumatologist, Pain management	Psychiatrist, Clinical Psychologist, Counsellor
<b>Sushila</b>	Fibromyalgia, myalgia parasthetica, arthritis, diabetes	Pains in the muscles, pains in the joints, back pain, sharp pain in bones, dizziness, insomnia	4	1	GP, Orthopaedic Surgeon, Neurologist, Rheumatologist, Gynaecologist, Pain management	Psychiatrist, Mental Health Nurse, Clinical Psychologist, Counsellor
<b>Kiran</b>	Fibromyalgia, chronic widespread pain, chronic pelvic pain, anxiety, depression	Pains in the muscles, pains in the joints, back pain, chest pain, headaches, fatigue, dizziness, blurred vision, insomnia, nausea, abdominal pain, shortness of breath	24	2	GP, Rheumatologist, Pain management	Clinical Psychologist, Counsellor

### **2.3.3 Research Procedure**

Service users expressing an interest in the study were given a copy of the participant information sheet by their keyworker (Appendix G). They were then contacted by the researcher to provide further information and offer them the opportunity to ask questions. Once their eligibility was confirmed, interview arrangements were made at a time and location preferred by the participant. Two participants chose to have their interviews conducted on healthcare service premises, and four participants chose to have their interviews conducted in their homes.

#### **2.3.3.1 *Materials***

In line with the principles of IPA, a semi-structured interview was chosen for data collection. The aim was to facilitate a comfortable interaction and invite participants to offer a rich, detailed account of their experiences of living with MUS and seeking support (Smith, Flowers & Larkin, 2009). The questions were based on the research questions but asked in a broad manner that allowed the participants to set the parameters of the topic and speak freely. It was hoped that this gave participants maximum opportunity to tell their own story, rather than the researcher imposing their own understanding of the phenomenon on the participants' account. An interview schedule was developed by the researcher and verified by the supervision team (Appendix J). It drew on guidance from relevant literature and previous IPA studies (Smith & Osborn, 2007), as well as the views of service users with MUS regarding its suitability. A demographic questionnaire was also administered, developed by the researcher in consultation with service users with MUS (Appendix I).

### 2.3.3.2 *Interview Procedure*

Prior to the interview commencing, participants gave written consent to take part in the study (Appendix H) and completed the demographic questionnaire (Appendix I). Semi-structured interviews were conducted in the participant's preferred language(s) and audio-recorded using an electronic dictaphone to enable an accurate record of the interview to be captured. Interviews lasted an average of 2 hours and 6 minutes, with the shortest being 1 hour 38 minutes, and the longest being 2 hours 25 minutes.

Following the interview, a debriefing sheet (Appendix L) was provided with details of support services. Participants were given the choice of reviewing the final themes from the study; four participants agreed they would do this. Those who did not wish to review the final themes had no further contact from the researcher following the interview.

### 2.3.3.3 *Ethical Considerations*

Ethical approval was gained from Coventry University, the Health Research Authority, and local Research & Development departments in recruiting National Health Service (NHS) trusts (Appendices C–E).

The researcher did not have access to the participants' healthcare records or other information from the recruiting team. They were reminded that withdrawal from the study would not affect their routine care or treatment, and that information shared with the researcher would be kept confidential unless it was deemed that there would be a risk of harm to the participant or someone else as a result of their actions.

It was considered that distress may arise from participants' sharing their experiences of difficult physical symptoms. A guide was used to support the researcher in assessing and

monitoring the level of risk shared by participants (Appendix K). Understandably, some participants became anxious, tearful, or otherwise distressed during the interviews, but felt able to continue and that immediate support was not required. A list of support services was provided during the debriefing and participants were encouraged to contact their GP or keyworker if they felt upset or concerned following the interview.

#### **2.3.4 Data Analysis**

Recorded interviews were transcribed verbatim by the researcher. For instances when the participant spoke Gujarati or Hindi (approximately 3% of all transcripts), the researcher used English transliterations to transcribe these sections and then forward-translated them according to the approach advocated by van Nes, Abma, Jonsson and Deeg (2010). For example, the researcher sat alongside an experienced interpreter to discuss possible wordings and chose fluid descriptions over literal translations. Transcripts were then analysed according to the IPA approach suggested by Smith, Flowers and Larkin (2009; Table 10). This involved a process of sustained engagement with the data and interpretation of each participants' accounts (Smith & Osborn, 2008).

Table 10. Stages of interpretative phenomenological analysis applied in the study.

Phase	Description
<b>Reading and re-reading</b>	Transcripts were read several times to allow the researcher to enter the participant's world and actively engage with the data. Audio recordings were also listened to repeatedly to facilitate further immersion in the data.
<b>Initial noting</b>	Exploratory comments were noted in the right-hand margin of printed transcripts to produce a comprehensive set of notes pertaining to participants' lived experiences. These comments related to three discrete processes: (1) descriptive comments focused on the content of the transcript, e.g. events, processes, objects, or phrases, (2) linguistic comments focused on the use and function of speech/language, and (3) conceptual comments questioned the narrative and reflected on the meaning of words or phrases for the participant and researcher. Descriptive comments were noted on the first reading, followed by more conceptual and linguistic comments on subsequent readings. Comments were also made regarding similarities, differences and contradictions in what the participants had said. This allowed the researcher to become increasingly familiar with the data and deepen the level of interpretative analysis.
<b>Developing emergent themes</b>	Emergent themes were noted in the left-hand margin of transcripts as short phrases or statements. These were generated by mapping the connections and patterns arising from the initial descriptive, linguistic and conceptual comments, as well as the original content of the transcript. They reflected the words of the participants but also represented the early stages of interpretative analysis. An example of an annotated transcript is included in Appendix M.
<b>Searching for connections across emergent themes</b>	Once emergent themes were identified, they were typed electronically and drawn together into related clusters. Attending to the context of each theme, as well as the specific function and relative frequency with which they appeared in the accounts, allowed for repeating themes to be identified. These 'higher-order' emergent themes were mapped visually to make sense of the relationship between themes and the predominant issues for each participant. A map of the themes for one participant is shown in Appendix N.
<b>Moving to the next case</b>	The phases above were applied to each participant's account until all six transcripts had been completed. Efforts were made to bracket the ideas from earlier transcripts, in keeping with IPA's commitment to idiography.
<b>Looking for patterns across cases</b>	The 'higher-order' emergent themes for participants were printed, using a different colour for each participant. These were mapped spatially to search for patterns and relationships between participants (Appendix O). Related themes were examined and clustered together, and cross-checked with the visual maps to examine the positioning and context of these themes. Those themes that were considered the most prominent and trustworthy across participant accounts were chosen. Final themes were discussed with the supervision team and slight revisions made to facilitate a coherent account of the participants' lived experiences.



#### 2.3.4.1 *Validity*

Yardley (2000) recommended attention to four broad principles to demonstrate the validity of IPA research. These are sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. These principles were considered throughout the research process to ensure validity. For example, sensitivity was established by reading the relevant literature and being mindful of the participants' cultural and social context, especially when conducting interviews in their homes. Transcripts were read multiples times and coded on two separate occasions, enabling a rigorous analysis. The analyses were shared with the supervision team who verified initial noting and emergent themes. Findings were also shared with four participants who agreed that the themes captured their lived experiences and were positive about the conclusions drawn. For transparency, Appendices M–O demonstrate the process of annotation and mapping of themes, and Appendix P contains additional interview extracts supporting the themes generated. Furthermore, clinical recommendations suggested directly by participants are detailed in Appendix Q to signify the importance of the research.

#### 2.3.4.2 *Reflexivity*

A central component of IPA is reflexivity, whereby the researcher engages in critical self-reflection throughout the research process. This is due to the researcher being actively involved in the collection, selection and interpretation of data. Research is, therefore, a co-created product shaped by the participants, researcher, and their relationship, unfolding a particular story which may not be unfolded by another researcher (Banister, Burman, Parker, Taylor & Tindall, 1994). It is therefore important to be aware of one's own

assumptions and preconceptions, in order to be open to the participants' meanings and maintain the quality of the research (Seale, Gobo, Gubrium, & Silverman, 2004).

Several strategies were employed to facilitate reflexivity: a bracketing interview was conducted with the supervision team to identify assumptions and pre-conceptions that may bias the research process. I became aware that my own lived experiences led me to view healthcare services as culturally insensitive, formed on Eurocentric values which inherently perceived Asian cultures as inferior to the White majority. Narratives in clinical practice and research reinforced that South Asian women with MUS were seen to lack insight and agency; I was keen to maintain an open mind about this, anticipating that participants may feel more comfortable elaborating on their views with me given that I shared characteristics with them as a British Indian woman.

A reflective diary was used to record personal reactions to ongoing procedures related to the research, such as recruitment and interviewing. Notes were also made following each interview, reflecting on initial impressions and interview dynamics. Frequent meetings with the supervision team enabled consideration of the potential influence of my role in different aspects of the research process, including data analysis and interpretations, thereby ensuring the quality of the research.

## 2.4 Findings

The study investigated the lived experiences of South Asian women with MUS. Three super-ordinate themes emerged from data analysis: *Multiple assaults on the self*, *Suffering in silence* and *Reconstructing the self* (Table 11). The women had endured traumatic experiences and managed multiple demands in their lives prior to their MUS, and then lost their agency and identity as a result of their pain symptoms. They faced shame and stigma from their communities and were consistently dismissed by professionals, leading to isolation and silent suffering. The women, therefore, made ongoing attempts to make sense of their MUS autonomously, by searching for explanations and navigating through resilience and support.

Table 11. Super-ordinate themes and sub-ordinate themes.

Super-ordinate themes	Sub-ordinate themes
Multiple assaults on the self	Fighting to survive through trauma
	Powerless against the pain
Suffering in silence	Shame, stigma and isolation
	Dismissed and alienated by professionals
Reconstructing the self	Struggling to find explanations
	Navigating resilience and support

Table 12 shows how the six sub-ordinate themes were derived and distributed across the six participants.

Table 12. Distribution of themes across participants.

Participant	Multiple assaults on the self		Suffering in silence		Reconstructing the self	
	Fighting to survive through trauma	Powerless against the pain	Shame, stigma and isolation	Dismissed and alienated by professionals	Struggling to find explanations	Navigating resilience and support
Jyoti	✓	✓	✓	✓	✓	✓
Champa	✓	✓	✓	✓	✓	✓
Amna	✓	✓			✓	✓
Nafisa	✓	✓	✓	✓	✓	✓
Sushila		✓		✓	✓	✓
Kiran	✓	✓	✓	✓	✓	✓

Each super-ordinate theme is described followed by each sub-ordinate theme. In order to improve the readability of findings, minor changes<sup>3</sup> have been made to interview quotes (Gilbert, Ussher, Perz, Hobbs, & Kirsten, 2010). Transcript line numbers are included in brackets for reference.

### **2.4.1 Super-ordinate theme 1: Multiple assaults on the self**

This super-ordinate theme represents the women's experience of suffering multiple assaults to their sense of self and identity. It includes two sub-ordinate themes: *Fighting to survive through trauma* and *Powerless against the pain*.

#### **2.4.1.1 Sub-ordinate theme 1: *Fighting to survive through trauma***

All five women who were first-generation immigrants described the process of migrating and settling in the UK as challenging. They were required to adjust to a "*different lifestyle*" (Amna: 44), and build a life even though "*you don't even know a single word in English, and you have to look after the family from scratch*" (Champa: 43-44). Many women described having to "*survive with very little money*" (Jyoti: 11) and therefore worked "*day and night*" (Champa: 12) to supplement the family's income.

Additionally, all six women described traumatic experiences in their lives, with setbacks and disappointments happening "*one after another*" (Champa: 449). Kiran reflected on her childhood experiences of emotional and physical abuse, and how being second-generation meant that "*you've got a dual identity, so you're going to have a crisis*" (594-595). Jyoti described numerous losses within a short space of time:

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<sup>3</sup> Repetitions or filler words e.g. "like", and hesitations e.g. "umm", have been omitted, as well as irrelevant words and sentences, indicated by ellipses (...). Words emphasised by participants in the interview are not italicised, and the addition of explanatory text for the purposes of clarity is denoted by square brackets [text].

*"I got divorced in 2001. And bringing up two young boys by myself as well. It was a very tough time in my life. But I did survive because of the job. And my divorce case lasted for four years. It was so stressful...I had a problem with the children, because you know when you're bringing them up by yourself, working seven days a week, I couldn't look after them properly [sobbing]...And, in between, my dad passed away, and within one and a half years, my mum, she passed away. And as soon as my mum passed away, within three weeks, my sister passed away. That did put me down a lot. But after that, I managed to pull myself until I had a fall..."*  
(75-83)

Jyoti talks about surviving through these tragic losses as a result of her job and her ability to "pull" herself together. Many participants described a similar process of fighting for their survival through their tragedies. Nafisa stated that *"every time, I fight for it. I didn't let it affect me, because I used to think, 'If I let this illness to ruin my life, what's going to happen to my children?'"* (Nafisa: 235-236). Resilience and determination to overcome their emotional pain, especially for the sake of their children, was apparent throughout the accounts.

However, the cultural and gendered roles and expectations these women were accustomed to, remained prominent. Amna describes how she felt burdened by the expectation to cook from her mother-in-law:

*"I used to start work at 8 o'clock in the morning, finish at 4 o'clock. After I come back, she was like, 'What are you going to cook today? You have to cook before tomorrow.' And I was like, 'I don't mind cooking, but don't just put it on me. You have to, like, we have to work together isn't it?' That's how things were going on...you come back from work and you just have to see the house, family, husband, everything." (84-90)*

The participants felt considerable pressure to fulfil their roles as wives, daughter-in-laws and mothers. This appeared to undermine the self-reliance they had worked so hard to build and often meant that their needs were sacrificed for others, with little self-care.

#### 2.4.1.2 Sub-ordinate theme 2: *Powerless against the pain*

In the midst of these struggles, the symptoms of pain slowly began to affect these women. Many ignored the symptoms initially and then took notice as the pain began “*growing more and more*” (Jyoti: 113), spreading to different parts of their body. This posed limitations on their ability to function as normal, yet many women were determined to continue fulfilling their previous roles. For example, Champa described the importance of her job:

*“I didn't want to let it go...I used to love work and love my job, that's why I didn't want to give it up. Despite my doctors telling me, literally, he said, ‘leave your job and concentrate on your health, I will write a sick note for you.’ But I didn't listen to him. I said, ‘No, I want to keep my job.’ It went for appeal and we lost the appeal, and then I had to go off sick.” (252-257)*

Champa’s account demonstrates the powerful nature of the symptoms; despite her determination, she was forced to leave her job even after appealing. She goes on to describe how her “*life is upside down*” (267) following these events, reinforcing the power and significance with which the pain changed her life.

Many of the women narrated similar experiences of losing their freedom and independence. Simple tasks which were once taken for granted were now described as impossible and required significant effort. As Sushila explained:

*“I can't do much...I am lucky if I can do like only for me. If I can shower and do myself, it's a big thing for me. Because, if you tell me to go and cook, how I'm going to cook with two sticks? And with the medication, I feel dizzy as well. It's not easy, it's not easy.” (554-557)*

The impact of the pain on Sushila’s life is even more apparent when compared to her identity in the past:

*“I was a lady with a lot of energy. And I was man of the house. After marriage as well, I used to go to work, come home, cooking, cleaning, my life, it was like full of joy. And suddenly, these things came, which I could not accept at all. Still now, sometimes, I don't accept, I go down*

*because the way I was, and the way I am now, I just feel like somebody took all my life and I'm on the zero side. I feel like I'm not useful...why I need to stay in this world, I don't deserve because hardworking and now you can't do anything, and it makes you upset.” (116-124)*

Her reference to herself as the “*man of the house*” illustrates how strong and authoritative she felt in the past, which emphasises the powerlessness she feels now when she describes herself as “*down*” on the “*zero side*”. Given her perceived loss of her previous identity, she refers to a difficult process of coming to terms with the changes in her life, seeming unable to accept the stark reality she is faced with.

## **2.4.2 Super-ordinate theme 2: Suffering in silence**

This super-ordinate theme represents the women’s experiences of their sense of self as hidden from view, due to their needs and feelings being consistently overlooked by others. It contains two sub-ordinate themes: *Shame, stigma and isolation* and *Dismissed and alienated by professionals*.

### **2.4.2.1 Sub-ordinate theme 1: *Shame, stigma, and isolation***

Although the symptoms were experienced as powerful and all-consuming, they were hidden by nature. Champa explained that “*if you see my face, if you see me on the road, you’re not going to think that I have this issue will you?*” (561-562). Since “*you cannot show anybody*” the pain (Nafisa: 286), the women felt that others did not take them seriously and judged them as dishonest. For example, Nafisa talked about others reactions towards her:

*“Because I have a walking stick, people won't say hello, they'll say ‘How much you getting for that?’ It's given me like a stigma...then they'll say like, ‘Oh, it doesn't look like you're ill.’ But it's not recognised. It's not like I've cut my hands. But...the pain is like I broken my leg.” (456-461)*



The potential to be stigmatised and judged left some women feeling despondent. Nafisa explained that *“nobody will understand that you cannot do things mentally, physically”* (484-485). Kiran elaborated on this:

*“But the thing is, it’s now taking an impact on my life, where I’m holding up queues or I’m dropping jars in supermarkets, because my grip isn’t strong enough, or it’s gone numb...and you know that embarrassment, that awkwardness, it’s making me not want to venture out. I made two friends at my daughter’s school and I haven’t been in touch with them for the last 2-3 weeks. And they’re like, ‘Where’ve you gone?’...that communication has slowly kind of died out...and if I explain to them, ‘Oh yeah I’ve got chronic pain’, ‘Oh, take a paracetamol, you’ll be fine!’ You know, people just don’t understand.”* (511-517)

Kiran’s account demonstrates how fear of shame or denial leads her to avoid communication with others. This shame was not only related to the women’s physical symptoms, but also to their previous traumatic experiences. For example, Nafisa described how she distanced herself from family:

*“I was finding very difficult to manage with my husband, all these problems [sigh]. Then I started hiding things from family, like you don’t want to say things, you don’t want to put yourself down...so I started closing up, not going to anybody.”* (152-156)

Fear of shame, gossip, or judgment from others, particularly from Asian society, led the women to isolate themselves. They, therefore *“lost all the contacts”* (Jyoti: 374) and became marginalised from their communities, suffering from their emotional and physical pain in silence.

#### 2.4.2.2 Sub-ordinate theme 2: *Dismissed and alienated by professionals*

All six women described experiences of feeling disregarded and dismissed by healthcare professionals; this mostly related to medical doctors, but also included nurses and allied health professionals. Champa explained how she *“was suffering for ages...but doctors said ‘Oh it happens to everyone in this country’. So I kept going but they just didn’t do anything”* (762-763).

Participants felt that their concerns were not taken seriously and that professionals were not interested in their lived experiences, as illustrated by Kiran:

*“All those years I've been coming and saying, ‘I've got this pain, I need help, I'm fatigued’, you know, they just fobbed me off with antidepressants. And it's so easy to give somebody antidepressants than to actually sit there...it's just taking that five minutes out, speaking to that patient, and exploring and understanding where they're coming from. And trying to understand what they're actually trying to say to you in between the lines...Not to just superficially diagnose whatever comes their way.” (263-267)*

Kiran appears to be yearning for someone to truly listen to the emotional pain underlying her physical symptoms. Nafisa elaborates on this:

*“I feel like they are very ignorant like, ‘Oh we can't do anything.’ But even if you can't do anything, at least you could say to me, ‘This is what's happening, that's your symptoms.’ You are the doctor. At least if you say to me, I'll be thinking like, ‘Okay, I'm alright. I'm not going mad.’ So that makes me wonder like, we live in a multicultural society...there is thousands of people who can't speak English, not a word, and they have an interpreter, or they their kids have to bring them. How they're going to cope? It's very difficult you know. That means our society suffers more, isn't it?” (784-790)*

Nafisa recognised that professionals have the power to reassure patients by hearing their concerns, and that differences in language mean that many people are unable to articulate their symptoms. The participants noted that there were no equivalent terms in their native languages for their bodily symptoms or the diagnoses they were given, which made it difficult for them to “*understand every bit of the medical way*” (Jyoti: 1037) and at times led them to worry about professional communication. Some women also described being sensitised to how healthcare professionals might judge them based on stereotypes of Asian women “*because apparently we're very meek, and we're vulnerable, and we're just going to listen to what they say*” (Kiran: 105-106). These experiences, together with instances of racism, contributed to feelings of frustration and alienation.

Many participants described a lack of effective service provision in the community, including from voluntary agencies and charity groups. Champa shared how she had *“tried so many places – one said they're not available, one I'm in the waiting list for...one said they're not gonna help me because I was under psychiatrist, and psychiatrist gave me something which was not appropriate for me...”* (636-641). Sushila also expressed frustrations about how healthcare services were *“sending me pillar to pillar, I've had enough”* (275). She went on to share her experiences with her psychiatrist:

*“...because she discharged me. She gave me the medication and she discharged me. She discharged me because she thought I'm under psychology. But psychology as well, they kicked me out. Now, both of them - I don't have anywhere to go...there are days I have low mood. And you know like, I don't have anyone to talk to.”* (679-684)

Sushila's account demonstrates her concerns about she will cope on her own. These feelings of abandonment made it especially difficult for those women who were already isolated from their communities. Healthcare services inadvertently repeated their previous experiences of feeling stigmatised, rejected and marginalised, and therefore perpetuated their silent suffering.

### **2.4.3 Super-ordinate theme 3: Reconstructing the self**

This super-ordinate theme represents women's longing for a more connected sense of self and identity. It includes two sub-ordinate themes: *Struggling to find explanations* and *Navigating resilience and support*.

#### **2.4.3.1 Sub-ordinate theme 1: *Struggling to find explanations***

All of the women described a lengthy process of investigations before they were formally diagnosed with chronic pain or fibromyalgia. Kiran described how she would *“go and do a*

*blood test, go and do some nerve testing, but they can't give you a diagnosis. So I've got to fight to actually be diagnosed with something*" (255-256). Champa also stated how she *"literally had to fight for her right"* to be sent for a magnetic resonance imaging (MRI) scan (771).

These struggles continued from diagnosis to treatment. Many women spoke about various medication being ineffective and *"not working"* for them (Sushila: 631), hypothesising that *"fibromyalgia...it's very subjective...the pain I'm going to experience and my threshold of pain, is going to be different to the next person's"* (Kiran: 323-324). This led some to seek alternative routes for treatment. Some women approached alternative therapists including holistic doctors, nutritionists, Ayurvedic practitioners and Chinese medicine, as well as having massages and acupuncture. Others sought treatments privately which were not financially sustainable.

The search for the alleviation of their symptoms was paralleled by the search for an explanation for their symptoms. Amna talks about how she noticed bodily symptoms in response to her mother-in-law:

*"The moment I used to get into the house, having that fear that, 'Oh my God, is she going to come here today?' Fear. And that's where it started, and I used to start feeling down a lot...Like the moment I used to see her I used to like, I don't know, my nervous system used to go down. My stomach used to give problems. I used to just get frightened and the moment I used to see her I would just start shaking, and my sugar level used to go down. That wasn't normal I think, that wasn't normal."* (113-117)

Her use of the phrases *"I don't know"* and *"I think"* demonstrate her apprehension and curiosity, although she appears certain that the symptoms started from fear. Similarly, Nafisa stated that *"a lot of things happened in my life...I was a stressed lady all the time...and you traumatise yourself...I'm actually 99% sure this is to do with that"* (338-339). Nafisa goes on

to say “*in my life, I find both of them going side by side, like depression and fibromyalgia. They trigger each other or something*” (348-350), a reflection also offered by other women.

Alternatively, Champa likened her body to a ‘human machine’ and suggested that the symptoms had arisen because the “*machine has become worn from inside, and you cannot replace those parts...you’ve got to live with it*” (473). Others considered the role of religious or spiritual explanations, such as *karma* (principle of cause and effect), *nazar* (evil eye), *kudrati* (fate), and *djinn* (supernatural creatures), but had mixed opinions about their influence.

Despite a variety of possible explanations, many struggled to grasp the changes to their life and identity, as examined by Kiran:

*“You sit back and you think, ‘Oh, am I really experiencing this pain?’ Well, I must do, because I used to be an accountant now I’m a customer service advisor. I used to work full-time, but now I’m part-time. Um, I never used to take any sort of painkillers, but now I take two every four hours. Yeah, why can’t I function? Why can’t I go out? You know, why can’t I sort of, socialize like other people do? Why am I having this anxiety?...Where is all this coming from?”* (326-334)

Kiran’s account reveals her struggle to make sense of the unexplained origins and nature of her pain, as well as its impact on her functioning. Her questioning “*why*” repeatedly suggests a yearning for answers.

#### 2.4.3.2 Sub-ordinate theme 2: *Navigating resilience and support*

In order to cope with their crippling MUS without adequate explanations, the participants looked elsewhere for support. Some women spoke about how their families not only helped with day-to-day tasks but also provided support and motivation. For example, Champa spoke about how her sons “*taught me how to live*” (121):

*“...the boys became teenagers, and like mature adults, they said ‘This is not right mum, all these health issues and depression and things you’re going through, it’s not your fault, you need to speak up’...And even like, still, boys keep telling me, ‘Mum, you’ve got to do whatever you think is right for you.’ So...last 4-5 years, I’ve started saying to people ‘No’ if it’s not right.” (76-78)*

Champa reflected on how this was different to what she was accustomed to, stating that her generation *“was brought up that way, just like... ‘you need to put family first, before yourself’”* (93-95). Likewise, Amna described how emotional support from her husband enabled her to become more assertive towards her mother-in-law:

*“She wanted to move in with us, and we just said no. Even though we said no, I still go and talk to her. She was a little bit upset with me for two days, for refusing her to come here. But then I had to, I had no choice.” (260-263)*

In addition to creating boundaries and improving self-care, Amna spoke about how her faith was integral in helping her to *“completely change my thought about her – the woman who bothered me so much”* (259):

*“I started going out and sitting in the religious talks, that was giving me a bit of peace of mind as well, ‘Look, you’re nothing in this world, you know, you rather worship God and be yourself, and you know, don’t let people affect you to be honest. There’s nobody for you. You just do what you want to do.’ That’s why I prepared myself like that, and kept all this in mind and just changed myself. Yes, I have. And that’s why I don’t really feel no symptoms of fibromyalgia anymore, to be honest, now.” (290-295)*

Amna’s account shows how her faith provided her with resilience and strength to overcome her symptoms. Other women also reported that faith in God provided a constant source of support and protection.

## 2.5 Discussion

This study explored the unique lived experiences of six South Asian women in the UK with MUS. It investigated how they understood and made sense of their MUS, coped with them day-to-day, and their experiences of seeking help and support. Three super-ordinate themes emerged: *Multiple assaults on the self*, *Suffering in silence* and *Reconstructing the self*.

The findings of this study show that South Asian women experienced their MUS in some ways that are similar to other ethno-cultural groups. All participants reported considerable loss of autonomy and identity following the onset of their symptoms. This is akin to other groups with MUS, whose pain engenders an ‘ontological assault’, jeopardising the conceptions of their body, identity and self (Crossley, 2000). This led to them becoming restricted and dependent in their daily life, negatively impacting on their roles and relationships.

The participants also experienced shame and stigma, since the severity of their symptoms were mostly disbelieved and dismissed by others. Smith and Osborn (2007) found that individuals with chronic back pain perceived shame in relation to their ‘entrapped selves’, which led them to feel embarrassed about their situation, vulnerable to criticism, and fearful of punishment. In order to reconcile their struggle of “coming to terms with shattered opportunities for daily life” (Lidén, Björk-Brämberg & Svensson, 2015), service users with MUS need to be considered reliable, and acknowledged as people with complex identities and life experiences, not only a diagnosis (De Silva, Bayliss, Riste & Chew-Graham, 2013; Dwamena, Lyles, Frankel & Smith, 2009; Lidén and Yaghmaiy, 2017).

The study also highlighted novel findings for this group. South Asian women with MUS clearly acknowledged and gave rich descriptions of traumatic experiences in their life,

including migration in their childhood, marital conflict, bereavement, racial discrimination, intergenerational struggles and their own social marginalisation. This contradicts previous claims that South Asian women are not ‘psychologically-minded’ since they are able to share their feelings when offered a safe space. The women considered these traumas as causal explanations for their MUS, alongside biological, social and spiritual explanations. Talking about common physical symptoms can serve as a socially acceptable vehicle to explore the links between a wide range of significant concerns (Kirmayer, Groleau, Looper & Dao, 2004). However, the participants reported that doctors rarely explored their emotional concerns alongside their physical symptoms, which may have prevented acknowledgement of the traumatic explanations for their MUS.

A number of disparities in diagnosis and treatment may be related to the overlooking of emotional concerns for this group. A large-scale household survey in England found that South Asian women were 12.5% more likely to have experienced a traumatic event compared to White or Black women, although diagnostic rates of post-traumatic stress disorder did not differ by ethnicity (McManus, Meltzer, Brugha, Bebbington & Jenkins, 2007). Additionally, in patients with depression, South Asian women were 18.4% less likely to receive psychological therapy compared to White women, despite higher GP consultation rates (Gater et al., 2009). Given that primary care services are the most accessible healthcare service available to people from marginalised groups in the UK (Dixon-Woods et al., 2005), South Asian women with MUS may need to “repeat encounters to receive desired or necessary care which they would otherwise be denied” (Hausteiner-Wiehle, Schneider, Lee, Sumathipala & Creed, 2011, p. 133).



Consistent with previous literature, the South Asian women in this study overwhelmingly reported poor quality consultations with healthcare professionals (Bayliss et al., 2014; Peacock, 2008). They were dismissed, misunderstood, and assessed against stereotypes of being ‘complainers’ or ‘submissive’ (Shah, 1989). Given the natural power imbalance between doctor and patient, such dismissal and alienation may silence patients. This silencing may pose particular challenges for South Asian women who disagree with their doctors’ suggestions, since their cultural background may value restraint or compliance with authority, and their intergenerational experiences of racism and colonial oppression may make it difficult or dangerous for them to assert their own opinion (Kirmayer, 2001). Despite this, many of the participants shared examples of ‘fighting for their rights’ and continued help-seeking for support. Given that their expression of distress and demand for medical attention may represent very rare occurrences in their lives, higher utilisation should instead be seen as a healthy expression of good self-care and assertion (Toner & Akman, 2000).

Higher utilisation may indicate efforts to “fit in with normative, biomedical explanations” and become a “credible patient” (Werner, Steihaug & Malterud, 2003, p. 1409). However, the women described being consistently pulled between physical and mental health services, leading to their needs being addressed in a disconnected manner, and at worst, them being abandoned by services due to professional miscommunication. Support from third sector organisations was also challenging to access due to their lack of organisation and availability. Given that the women experienced isolation from their wider communities, they often could not access alternative sources of support. With inconsistent professional support and abandonment by services, patients with MUS can lose their confidence and trust in professionals (Lidén and Yaghmaiy, 2017).

It has been argued that “one of the basic tasks of the clinical encounter is the co-construction of meaning for distress...that make sense to patients and their families” (Kirmayer, Groleau, Looper & Dao, 2004, p. 670). Although participants could not identify equivalent terms for their depression or MUS in their native languages, they were able to conceptualise their distress in their own terms and according to their own ‘cultural idioms’, similar to previous studies with South Asian samples (Fenton & Sadiq-Sangster, 1996; Mallinson & Popay, 2007; Rogers & Allison, 2004). While these do not fit with biological theories, they are sufficient to give meaning to distress, guide help-seeking and healthcare utilisation, and can relieve suffering (Kirmayer, Groleau, Looper & Dao, 2004; Pennebaker & Seagal, 1999). Thus, by focusing only on the biomedical aspects of their stories, participants were effectively ‘somatised’ by the clinical consultation and wider medical system (Greco, 2017), and left unable to construct a meaningful narrative about their experiences. MUS may, therefore, be better conceptualised as ‘medically unexplained stories’ (Launer, 2009).

Although shame has been recognised to affect people with MUS, this appeared to be amplified for the women in this study. In order to maintain safe and intimate relationships, women have been socialised to be compliant, understanding, never overtly angry, and to please others instead of giving priority to themselves (Toner & Akman, 2000). The participants demonstrated this by silencing and sacrificing their own needs, leading to internalised anger and loss of self (Jack, 1991). Moreover, they reported the potential to be judged and shamed by their communities in relation to their loss of ability to fulfil cultural and gendered roles and expectations. The collectivist values of South Asian cultures may influence this tendency to comply for the greater good, as shame reflects not only on the self but also on the family and community (Gilbert et al., 2007). Whereas these values could enable some people to gain support and resources, others may be abandoned,

positioning the collective family and community as a ‘double-edged sword’ (Shorer, Goldblatt, Caspi & Azaiza, 2018).

Understanding the contribution of psycho-social determinants of distress can open up more meaningful interpretative possibilities, validate and normalise suffering, and call for redress in social, economic and political systems (Kirmayer, Groleau, Looper & Dao, 2004). However, rather than addressing these psycho-social determinants, the observed ‘medicalisation of distress’ results in a focus on treating individuals (LaFrance, 2009; Ussher, 2010). These ‘somatising effects’ may be linked to certain features of the medical profession, including a culture of medical treatment and ‘trauma-phobia’ in doctors due to inadequate models of training (Maté, 2015), attempts to maintain authority in the face of ambiguous symptoms due to their own feelings of anxiety and inadequacy (Wileman, May & Chew-Graham, 2002), and multiple and unnecessary medical investigations due to a fear of overlooking a genuine organic cause (Reid, Wessely, Crayford & Hotopf, 2001). This latter motive may be associated with a culture of defensive practice arising from a fear of litigation and media exposure (Bourne et al., 2017).

### **2.5.1 Implications for policy and clinical practice**

Political campaigns and media coverage could help to raise awareness and educate lay people about the reality of the underlying reasons for MUS, alongside education to develop a better understanding. Services could promote ‘champions’ for MUS to raise this agenda and encourage a dialogue between professionals and service users, to develop greater understanding, knowledge and skills.

A clinical approach that involves careful enquiry and a holistic approach is needed, by integrating the physiological aspect of symptoms with the emotional, social and spiritual

aspects of patient's life experiences (Naylor et al., 2016). Explanations should be offered as a 'wager on the unfinishedness of the present', acknowledging the limited knowledge we currently have of the complex pathways and feedback loops between biological, psychological and social events, rather than prioritising simple causal mechanisms (Greco, 2017). Training and supervision could help medical professionals to integrate these aspects and manage their own feelings of incompetence to improve patient outcomes (Launer, 2009). Also, guidance for healthcare professionals such as those provided by The Forum for Mental Health in Primary Care needs to be integrated into routine clinical practice (Chitnis et al., 2011). This could be supplemented by training in approaches such as emotion-focused interviewing, which has been found to increase the confidence of medical professionals in responding to and managing MUS in primary care settings (Abbass, 2005).

The stepped care approach to the management of MUS needs to extend beyond a medical conceptualisation to psycho-social interventions which are culture and gender-sensitive, trauma-informed, and person-centred. Wider access to peer support groups may help to alleviate some of the reported isolation, normalise and validate experiences, and increase resilience by attempting to re-establish 'ontological security' (Crossley, 2000). Furthermore, promoting 'experts by experience' to share their experiences of living with and overcoming MUS, may also support and empower service users to cope with their symptoms. Specific recommendations suggested by the interviewed participants are outlined further in Appendix Q.

### **2.5.2 Strengths and limitations of the study**

It is acknowledged that the use of the term 'South Asian' is problematic. Despite sharing a similar geographical region, this group is made up of a variety of languages, faiths, and

cultural traditions (Bhopal, 1997). Although they may operate within a given cultural frame of reference, the degree in which they subscribe to the associated norms may vary (Consedine & Soto, 2014).

Furthermore, a small number of participants were interviewed. Although IPA methodology favours small sample sizes to facilitate in-depth idiographic explorations, care must be taken not to make broad generalisations. Participants were recruited from specialist community services familiar with referrals for MUS, which may mean their experiences are specific to their encounters with the healthcare system in that context.

A strength of the study is that it has considered the specific views of South Asian women with MUS without attempting to make comparisons. It has also attempted to raise awareness of the quality of care perceived by this group, rather than promote aetiological understandings, a limitation of research into ethnicity (Bhopal, 1997). Given that there was overlap between the findings of this study and previous qualitative studies of South Asian women with MUS, the findings indicate several similar clinical and policy implications deserving adequate attention.

### **2.5.3 Recommendations for future research**

Given that participants reported struggling to come to terms with their fragmented sense of self, future research could explore the factors that promote and encourage acceptance and coping in South Asian women with MUS. A peer support group based on a trauma-informed and resilience framework could be implemented and evaluated to facilitate this.

Although the somatic symptoms and diagnoses overlapped considerably between participants, the duration of symptoms ranged from 4-30 years. Exploring the perceptions and needs of South Asian women with MUS at different stages of presentation may help

healthcare professionals to elucidate appropriate strategies to implement at each stage, in order to encourage positive coping and resilience. Given that this study focused on women, future studies could focus on the lived experiences and specific needs of South Asian men with MUS.

More research is needed to understand the conceptualisation of distress in healthcare encounters. Attending to the views of healthcare professionals could shed light on their perception of barriers to exploring trauma and emotional concerns in this population, and help to identify strategies to address this. Positive examples of healthcare utilisation in South Asian women with MUS could further help to inform strategies more widely and share best practice.

## 2.6 Conclusion

This study explored the lived experiences of six South Asian women with MUS in the UK. The findings indicate that these women can have multiple traumatic experiences in their lives which are silenced by gendered social norms and cultural roles and expectations. This results in them becoming isolated and facing difficulties in accessing support. Healthcare services reinforce experiences of silencing and traumatisation by dismissing their emotional needs in healthcare consultations, medicalising their distress, and ignoring the cultural context of their lives. This exacerbates their emotional and physical pain, perpetuating somatisation. It can, therefore, be argued that higher healthcare utilisation in South Asian women with MUS is not purely an outcome of differences in morbidity or socio-cultural norms, but an interaction between multiple psycho-social factors that are exacerbated by poor quality encounters with the healthcare system.

In order for South Asian women with MUS to achieve a level of coping and acceptance of their symptoms, and a coherent life narrative in spite of their symptoms, healthcare services need to be more attuned to the lived embodied experience of trauma within this population. Professionals must develop an attitude of open-mindedness and willingness to explore how emotional stress can impact upon health and wellbeing, and develop the necessary knowledge and skills to implement a more culture and gender-sensitive model of care that increases the resilience of South Asian women with MUS.

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## **CHAPTER 3 – REFLECTIVE PAPER**

### **Managing conflicts between personal and professional identities: a reflective account**

This paper has not been prepared for submission to any journal

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### **3.1 Introduction**

This chapter discusses my reflections on the process of conducting research as part of my doctoral training in clinical psychology. The systematic literature review utilised the meta-ethnographic approach to investigate the experiences of seeking help for mental health problems and the perceptions of barriers to accessing primary mental health care, as reported by South Asian adults in the United Kingdom (UK). The empirical paper explored the experience of living with and seeking support for, medically unexplained symptoms (MUS) in six South Asian women in the Midlands region of the UK. My personal reflections mostly pertain to the empirical study and are drawn from a research diary kept throughout the research process. A number of themes were identified, including researcher's positionality, challenges with recruitment, and interviewing and analysis. Each theme is discussed in turn, followed by reflections on the impact of the research and these challenges on my personal and professional development.

## **3.2 Acknowledging my position**

### **3.2.1 Reflexivity**

The process of reflexivity is key to both working as a trainee clinical psychologist and conducting qualitative research. Reflexivity refers to the ability to attend, acknowledge and mediate the impact of a researcher's position and background on "their choice of research topic, the angle of investigation, the methods judged most adequate for the research purpose, the findings considered most appropriate, and the framing and communication of conclusions" (Malterud, 2001, p. 483). Researchers are advised to consider their "presuppositions, choices, experiences, and actions during the research process", as well as their personal experiences and values that may have influenced their research interests (Harrison, MacGibbon & Morton, 2001, p. 325). Considering this, I consciously acknowledged my position prior to clinical training and undertaking the current research.

### **3.2.2 Researcher background**

I identify myself as a working-class British Indian Gujarati female. My family have strong religious, spiritual, and cultural traditions, and these values continue to form a core part of my identity today. Being brought up in a diverse city in the UK, I had the privilege to imbibe values from the Hindu religion and Indian culture and came to appreciate the many ways in which they fostered psychological wellbeing and resilience among individuals and communities. However, knowing friends and family with mental health difficulties, I became acutely aware of the challenges in seeking help from mental health services. My reading of the literature led me to understand some of the factors related to this, but these appeared to be mostly positioned as 'cultural barriers' that pathologised South Asian

culture for hindering people from seeking help (Burr, 2002). Those I knew with mental health difficulties did not receive appropriate support from services, but this was not due to a lack of effort or engagement. This led me to believe there was more to lower utilisation than only ‘cultural barriers’. I, therefore, set out undertaking this research project with the intention of giving South Asian service users a voice.

### **3.2.3 Being an ‘outsider’**

Coming onto clinical psychology training was a huge culture shock for me; not only was it the first time in my life that I was the ethnic minority in a group, but it was the first time that I felt I had to compartmentalise my values and beliefs as an Indian and Hindu woman. I found myself battling between two aspects of my identity; described aptly by one of the women I interviewed:

*“...because you have that sort of realisation a lot earlier on, a lot of the mainstream culture you don't fit into. So you live in this dual identity. You speak in English outside the home, but Punjabi inside the home. You're trying to sort of always trying to fit in, but you belong in neither...So it's that, you know, that identity crisis.”* (Kiran: 186-192)

Although I had been in many diverse spaces growing up, this inability to belong was something I only experienced after joining training; the speaking ‘English’ was, therefore, more about speaking ‘clinical psychology’. I experienced the profession as seemingly ignorant of its colonial backdrop and racial biases, which prevented an honest examination of the powerful and silencing nature of its inherent ‘Whiteness’ (Wood & Patel, 2017). Experiences in teaching and training reminded me of the stark differences in the cultural approaches being taught in clinical training and those I was brought up with (Prajapati, Kadir & King, under review). This led me to wonder that if I, a British-born female, who was fairly well educated and acculturated, felt alienated from this culture of mental health



and clinical psychology; how might people with mental health difficulties, who are more affiliated with their cultural identity or who do not have the same privileges as me, feel when coming into contact with services?

In some ways, this culture clash led to an *assault on my sense of self*. Similar to the participants, I underwent a process of feeling like I had lost a part of my previous identity as I could not fulfil all the values and practices I was accustomed to. Developing a new identity as a trainee clinical psychologist formed on Western and Eurocentric values and practices was something I felt ambivalent about, and asserting these ideas in clinical spaces made me feel like a fraud. I began searching for answers and explanations, seeking out support and guidance, to learn how I could *reconstruct myself* as an Indian trainee clinical psychologist. In the midst of these dilemmas, I chose to undertake the current research related to South Asian people's mental health.

### **3.2.4 Being an 'insider'**

Given that I shared some characteristics with the women I interviewed; being a South Asian woman living in the UK, it was important for me to be reflexive about the impact this could have on the research process. During the interviews, I noticed many dimensions of commonality. For example, when the women I interviewed were narrating their difficult experiences of migrating to the UK and settling into a foreign country, I was prompted with memories of my own family narrating similar experiences to me. However, other aspects were less familiar, such as their experiences of living with chronic pain, or their role as a mother, which I had not experienced personally. Song and Parker (1995) stated that there are numerous dimensions along which researcher and participant may claim commonality or difference, and so there are likely to be multiple connections and disconnections through the course of an interview.

It was important for me to recognise when I felt a sense of familiarity, as this could have influenced the analysis and conclusions drawn from the women's accounts (Hunter, 2010). In order to reduce the risk of my own beliefs and assumptions clouding the process, I gave participants the opportunity to elaborate on their meanings and interpretations, by asking questions like "could you say more about that?" or "what does that mean to you?". Re-reading interview transcripts ensured that I engaged with the participants' meanings, rather than imposing my own. Research supervision also allowed me to discuss my thoughts and remain reflexively aware of my beliefs and assumptions.

It is also important to note that a sense of familiarity and shared characteristics could have led participants to withhold or disclose certain information (Willing, 2008). The research included in the systematic review revealed that South Asian service users could perceive Asian professionals to be judgmental as they "*gossip and judge regardless of what they may say to their bosses*" (Moller, Burgess & Jogiyat, 2016, p. 206). Although it was impossible to know what participants may have censored in the interviews, they did appear comfortable in sharing their experiences with me. This was partly indicated by the length of time they were willing to speak to me, most for over two hours, which was longer than I had anticipated.

Shared characteristics have been suggested to facilitate the research process, as "women who have some shared experiences with researchers may be more willing to speak to researchers who reflect this" (Bhopal, 2001). This was apparent in the interviews by the women's use of phrases such as "you know what I mean" or "obviously you understand as you're Asian" when referring to cultural terms or traditions. More often than not, I did understand, and I would respond by nodding my head and smiling encouragingly. Some women also preferred to explain their experiences in Gujarati, which I was able to

accommodate comfortably due to this being one of my own languages. Being an ‘insider’ was therefore advantageous in this study, as our mutual understanding facilitated trust, ease, and rapport.

### **3.3 Managing challenges with research methodology**

#### **3.3.1 Recruitment**

An initial challenge I faced when carrying out the research was in recruiting South Asian women with MUS. I was already aware that South Asian participants faced challenges to being represented in health research studies (Quay, Frimer, Janssen & Lamers, 2017), and was hopeful that my research would give them a platform to be heard. Initially, I approached services familiar with service users presenting with MUS, including liaison psychiatry services. Gatekeepers appeared to have different reactions towards my research; some appeared interested and eager to learn more, whilst others were more reserved and suspicious. Given the literature on the high utilisation of services by South Asian women with MUS (Sutton et al., 2002), I was surprised to hear that many of these services did not have any South Asian women with MUS on their caseloads. I wondered whether this supported the inconsistencies in the literature regarding the rates of somatisation, or if gatekeepers played more of a role than I anticipated in determining the likelihood of recruiting this group.

I, therefore, decided to take another tactic and advertised the research in local community centres and temples. Being able to speak Gujarati, I shared details of the study to a congregation of Indian women at a religious festival and was met with enthusiasm and interest by members of the community and organisational leaders. For example, one woman made suggestions about how I could increase the visibility of the study by speaking

at a larger formal gathering, rather than advertising a poster on their noticeboard. Reflecting on the reasons for more helpful responses from community organisations, I wondered if this was influenced by my ethnic identity, which perhaps engendered more trust; if they wanted to help me succeed, since I knew some members in the temples from a young age; or if it was because they deemed the research worthwhile. In some ways, challenges with recruitment reflected my earlier experiences of feeling like an ‘outsider’ in clinical settings, yet being an ‘insider’ with those who shared similar characteristics to myself.

### **3.3.2 Finding a balance between roles**

Another way in which I found myself experiencing some conflict was between my role as a trainee clinical psychologist and researcher when conducting the interviews. This conflict has been acknowledged by Haverkamp (2005), who emphasised the internal conflict between a therapists’ clinical obligation to act in the participants’ best interests, and the researcher’s mandate to pursue answers to research questions with appropriate rigour. The women I interviewed shared a number of traumatic and sensitive experiences with me, including bereavement and marital conflict, or racist treatment from healthcare professionals. Many were also depressed and some shared details of their suicidal thoughts and previous attempts with me. Given that therapeutic skills were integral to the role of both trainee clinical psychologist and researcher, it was difficult to maintain a neutral stance to their feelings of anger or sadness. The methodology of interpretative phenomenological analysis (IPA) required me to minimise interruptions and allow women to tell their own story (Smith, Flowers & Larkin, 2009). I, therefore, had to learn to resist the urge to explore their emotional needs, or offer a psychological intervention, in order to not jeopardise the quality of the data collected.

However, this restraint often felt disempowering; on occasion, I left an interview feeling extremely sad and wondered how the participant was going to cope with their low mood and unpredictable MUS in the future. This was more concerning to me because many of the women described feeling isolated and abandoned in their accounts, with minimal support from healthcare services. They asked if there were support groups in the community for women like themselves, or if I could facilitate a meeting with other participants. Although a list of support services was provided as part of the debriefing, I had not planned to establish a group as part of the research study, and yet I felt responsible for ensuring their ongoing wellbeing. This enquiry left me feeling guilty that I was not doing enough to support them, that I was dismissing or abandoning them, reinforcing their previous encounters with healthcare services, and that my engagement with them had inadvertently become tokenistic, which is not what I had set out to achieve through this research.

To manage this conflict, it became important to remind myself that simply meeting an interested listener had benefit in itself. Indeed, most of the women concurred with this sentiment, by indicating that they had found the interview cathartic and helpful to share their views. In hindsight, their wish to seek support from others and share their experiences may have motivated their willingness to speak with me for the length of time they did; and similarly, my desire to give them a voice motivated me to oblige to empower them further.

### **3.3.3 Data analysis and interpretation**

I found data analysis to be the most challenging aspect of the research process, perhaps reflecting the fact that I was a novice using IPA methodology. Having been mindful of not taking the role of a therapist during the interviews, I assumed that this separation should naturally extend to the analytic stage. However, I later realised that this approach, together

with my efforts to stay grounded in the data and bracket my own beliefs or assumptions from influencing the process, had led to codes which were initially too cautious and descriptive. IPA is meant to be an iterative process of fluid engagement with the data, where one immerses oneself in the participant's world through multiple readings of the data (Smith, Flowers & Larkin, 2009). In order to develop stronger interpretative claims, I returned to guidance on conducting IPA and coded all six transcripts with a more interrogative and conceptual lens. At times this felt uncomfortable, as though I was formulating the clients' experiences without their consent; the images and metaphors I produced were not far from the interpretations I would offer in therapeutic relationships. However, this process of repeated coding allowed me to explore different avenues of meaning and extend the analysis to a more interpretative level.

Subsequent stages of developing super-ordinate themes, where patterns and connections between the emergent themes are explored, was also challenging. I felt overwhelmed by the richness of the data and uncertain about how I could produce themes which would capture and honour the essence of participants' experiences. Discarding themes felt as though I was discarding the value of some of their experiences. I also found myself stuck between alternative ways of presenting the data since each construction shed light on a slightly different aspect of the participants' accounts. This is where the 'interpretative' aspect of IPA came to the fore for me; how I chose to convey the final themes appeared to convey my own understanding of what was most pertinent in the participants' account of their experiences.

Doubts and concerns about what constituted a 'good enough' representation also clouded the process. I had to remind myself that there was no 'right' or 'perfect' story, and therefore not to place such high expectations on myself. Stepping away from the data and returning

with a clear mind helped me to focus on what was important for both the participants and myself. Discussing my interpretations and themes with peer trainee clinical psychologists and research supervisors enabled me to analyse the data from different perspectives, which aided in clarifying my understanding of the accounts. The participants also eased my concerns about over-interpreting by validating the findings and providing positive feedback.

### 3.4 Closing the hermeneutic circle

In many ways, a parallel process emerged between the participants' experience of their MUS and my own experiences of being a minority in clinical training. For example, for a long time, I also *suffered in silence* about my 'identity crisis'. Many doubts were raised about which aspects of my identity I should value more, and in which contexts. At times, I felt incredibly isolated with these uncertainties. Turning to various avenues, including peers and tutors, I struggled to find any concrete explanations for the conflict I was experiencing. I also wondered if there were support groups I could attend, or if I could meet other trainees with shared experiences, similar to the women I interviewed.

One thing that struck me about their accounts however, was their determination and resilience. Despite a number of traumatic experiences, multiple demands and expectations between work and home, and their subsequent MUS, many women showed great courage to continue fighting for themselves and their families. I was in awe of their ability to remain hopeful, and their wish to help other women with MUS through participating in the study, even while they were still suffering from pain themselves. I feel truly honoured to have interviewed these six women and grateful for their openness and honesty in sharing their experiences with me. Their stories have made me realise that sometimes there are no easy or simple answers and that *reconstructing myself* is a lifelong journey. However, with courage, resilience, and hope, it is possible to face the challenges of life and its uncertainties.



### **3.5 Conclusion**

Commencing my empirical research with the intentions of giving a voice to South Asian women and their mental health needs, I did not foresee the impact this process would have on my own personal and professional development. Navigating through the challenges presented in the research process, I have learnt to be more flexible, thorough, and yet pragmatic about how I approach research methodology. Reflecting on the research process has further highlighted the importance of reflexivity, and allowed me to consider the reciprocal impact that conducting research can have on both the participants and the researcher. Through applying IPA and meta-ethnography, I have come to appreciate the value of qualitative methods and the insight they can bring to understanding health-related issues. This has generated an enthusiasm to conduct further qualitative research in the future.

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## Appendix A – Search Strategy for Literature Review

**Database: PsycINFO (1987 to March 2019)**

*Platform: Ovid*

1. ("south asia\*" or Asian\* or Bangladesh\* or Bengal\* or Gujarat\* or India\* or Lanka\* or Pakistan\* or Punjab\* or Tamil\*).tw.
2. asians/
3. exp south asian cultural groups/
4. 1 or 2 or 3
5. ("mental health" or "mental illness" or disorder or distress or "mental adj3 service\*" or "psycholog\* adj2 service\*" or "primary care" or "community mental" or CMHT or psychotherap\* or therap\* or counsel\*).tw.
6. exp Mental Health/
7. exp Mental Disorders/
8. exp Psychological Stress/
9. exp Mental Health Services/
10. exp Primary Health Care/
11. exp Community Mental Health Services/
12. exp PSYCHOTHERAPY/
13. 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12
14. (accept\* or access\* or barrier? or challeng\* or engag\* or exclu\* or hind\* or limit\* or obstacle? or pathway? or "use" or utili\* or "help?seeking" or "seek\* adj3 help" or "seek\* adj3 support").tw.
15. exp Health Care Utilization/
16. exp Help Seeking Behavior/
17. exp Health Care Seeking Behavior/
18. exp Treatment Barriers/
19. 14 or 15 or 16 or 17 or 18
20. (qualitative or interview\* or "focus group\*" or "content analysis" or "discourse analysis" or ethnograph\* or "grounded theory" or "mixed?method\*" or narrative\* or phenomenolog\* or "thematic analysis").mp.
21. (Engl\* or Scot\* or Wales or Welsh or "Northern Ireland" or "United Kingdom" or UK or "Great Britain" or Brit\*).mp.
22. 4 and 13 and 19 and 20 and 21
23. limit 22 to last 20 years

*Search results = 280*

*Search field codes:*

tw = includes table of contents, title, abstract, and key concepts

mp = title, abstract, heading word, table of contents, key concepts, original title, tests & measures

**Database: MedLine (1946 to March 2019)**

*Platform: Ovid*

1. ("south asia\*" or Asian\* or Bangladesh\* or Bengal\* or Gujarat\* or India\* or Lanka\* or Pakistan\* or Punjab\*).ti,ab,kw.
2. exp Asian Continental Ancestry Group/
3. INDIA/
4. BANGLADESH/
5. PAKISTAN/
6. Sri Lanka/
7. 1 or 2 or 3 or 4 or 5 or 6
8. ("mental health" or "mental illness" or disorder or distress or "mental adj3 service\*" or "psycholog\* adj2 service\*" or "primary care" or "community mental" or CMHT or psychotherap\* or therap\* or counsel\*).ti,ab,kw.
9. exp Mental Health/
10. exp Mental Disorders/
11. exp Stress, Psychological/
12. exp Mental Health Services/
13. exp Primary Health Care/
14. exp Community Mental Health Services/
15. exp PSYCHOTHERAPY/
16. 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15
17. (accept\* or access\* or barrier? or challeng\* or engag\* or exclu\* or hind\* or limit\* or obstacle? or pathway? or "use" or utili\* or "help?seeking" or "seek\* adj3 help" or "seek\* adj3 support").ti,ab,kw.
18. exp Health Services Accessibility/
19. exp Communication Barriers/
20. exp Health Care Utilization/
21. exp "Patient Acceptance of Health Care"/
22. exp "Delivery of Health Care"/
23. 17 or 18 or 19 or 20 or 21 or 22
24. (qualitative or interview\* or "focus group\*" or "content analysis" or "discourse analysis" or ethnograph\* or "grounded theory" or "mixed?method\*" or narrative\* or phenomenolog\* or "thematic analysis").mp.
25. (Engl\* or Scot\* or Wales or Welsh or "Northern Ireland" or "United Kingdom" or UK or "Great Britain" or Brit\*).mp.
26. 7 and 16 and 23 and 24 and 25
27. limit 26 to last 20 years

*Search results = 318*

*Search field codes:*

ti = title

ab = author-written abstracts

kw = author keywords assigned by indexers

mp = title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol

supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms

## Database: Embase (1980 to March 2019)

Platform: Ovid

1. ("south asia\*" or Asian\* or Bangladesh\* or Bengal\* or Gujarat\* or India\* or Lanka\* or Pakistan\* or Punjab\*).ti,ab,kw.
2. exp South Asian/
3. 1 or 2
4. ("mental health" or "mental illness" or disorder or distress or "mental adj3 service\*" or "psycholog\* adj2 service\*" or "primary care" or "community mental" or CMHT or psychotherap\* or therap\* or counsel\*).ti,ab,kw.
5. exp mental health/
6. exp mental disease/
7. exp mental stress/
8. exp mental health service/
9. exp primary medical care/
10. exp community mental health/
11. exp psychotherapy/
12. 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11
13. (accept\* or access\* or barrier? or challeng\* or engag\* or exclu\* or hind\* or limit\* or obstacle? or pathway? or "use" or utili\* or "help?seeking" or "seek\* adj3 help" or "seek\* adj3 support").ti,ab,kw.
14. exp help seeking behavior/
15. exp health care access/
16. exp health care utilization/
17. exp health care quality/
18. 13 or 14 or 15 or 16 or 17
19. (qualitative or interview\* or "focus group\*" or "content analysis" or "discourse analysis" or ethnograph\* or "grounded theory" or "mixed?method\*" or narrative\* or phenomenolog\* or "thematic analysis").mp.
20. (Engl\* or Scot\* or Wales or Welsh or "Northern Ireland" or "United Kingdom" or UK or "Great Britain" or Brit\*).mp.
21. 3 and 12 and 18 and 19 and 20
22. limit 21 to last 20 years

Search results = 530

### Search field codes:

ti = title

ab = author-written abstracts

kw = keywords defined by the author of the article

mp = title, abstract, heading word, original title, keyword, floating subheading word, candidate term word

## Database: Cumulative Index to Nursing and Allied Health Literature (CINAHL)

Platform: EBSCO

- S1 "south asia\*" or Asian\* or Bangladesh\* or Bengal\* or Gujarat\* or India\* or Lanka\* or Pakistan\* or Punjab\*
  - S2 (MH "Asians")
  - S3 (MH "Asia, Western+")
  - S4 S1 OR S2 OR S3
  - S5 "mental health" or "mental illness" or disorder or distress or "mental N3 service\*" or "psycholog\* N2 service\*" or "primary care" or "community mental" or CMHT or psychotherap\* or therap\* or counsel\*
  - S6 (MH "Mental Health+")
  - S7 (MH "Mental Disorders+")
  - S8 (MH "Stress, Psychological+")
  - S9 (MH "Mental Health Services+")
  - S10 (MH "Primary Health Care+")
  - S11 (MH "Community Mental Health Services+")
  - S12 (MH "Psychotherapy+")
  - S13 S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12
  - S14 accept\* or access\* or barrier# or challeng\* or engag\* or exclu\* or hind\* or limit\* or obstacle# or pathway# or "use" or utili\* or "help#seeking" or "seek\* N3 help" or "seek\* N3 support"
  - S15 (MH "Help Seeking Behavior+")
  - S16 (MH "Health Services Accessibility+")
  - S17 (MH Communication Barriers+)
  - S18 (MH "Quality of Health Care+")
  - S19 S14 OR S15 OR S16 OR S17 OR S18
  - S20 qualitative or interview\* or "focus group\*" or "content analysis" or "discourse analysis" or ethnograph\* or "grounded theory" or "mixed?method\*" or narrative\* or phenomenolog\* or "thematic analysis"
  - S21 Engl\* or Scot\* or Wales or Welsh or "Northern Ireland" or "United Kingdom" or UK or "Great Britain" or Brit\*
  - S22 S4 AND S13 AND S19 AND S20 AND S21
- Limiters – Published Date: 19990101-20191231

*Search results = 396*

*Search fields:*

Default text search = title, abstract, subject headings

**Database: Web of Science (Indexes = SSCI; Timespan = 1999-2019)**

*Platform: ProQuest*

- #1 TS=("south asia\*" or Asian\* or Bangladesh\* or Bengal\* or Gujarat\* or India\* or Lanka\* or Pakistan\* or Punjab\*)
- #2 TS=("mental health" or "mental illness" or disorder or distress or "mental NEAR/3 service\*" or "psycholog\* NEAR/2 service\*" or "primary care" or "community mental" or CMHT or psychotherap\* or therap\* or counsel\*)
- #3 TS=(accept\* or access\* or barrier\$ or challeng\* or engag\* or exclu\* or hind\* or limit\* or obstacle\$ or pathway\$ or "use" or utili\* or "help\$seeking" or "seek\* NEAR/3 help" or "seek\* NEAR/3 support")
- #4 TS=(qualitative or "mixed\$method\*" or "focus group\*" or interview\* or "content analysis" or "discourse analysis" or ethnograph\* or "grounded theory" or narrative\* or phenomenolog\* or "thematic analysis")
- #5 CU=(Engl\* or Scot\* or Wales or Welsh or "Northern Ireland" or "United Kingdom" or UK or "Great Britain" or Brit\*)
- #6 #1 AND #2 AND #3 AND #4 AND #5

*Search results = 368*

*Search field codes:*

TS = Topic (title, abstract, author keywords and keywords plus)

CU = Country/Region

## Database: Applied Social Sciences and Abstracts (ASSIA)

Platform: ProQuest

- S1 ti("south asia\*" OR Asian\* OR Bangladesh\* OR Bengal\* OR Gujarat\* OR India\* OR Lanka\* OR Pakistan\* OR Punjab\*) OR ab("south asia\*" OR Asian\* OR Bangladesh\* OR Bengal\* OR Gujarat\* OR India\* OR Lanka\* OR Pakistan\* OR Punjab\*) OR su("asian people" OR "punjabi speaking people" OR "english-tamil speaking people" OR "pakistani people" OR "indian people" OR "south asian studies" OR "sri lankan people" OR "south asian cultural groups" OR "south asian communities" OR "bengali people" OR "gujarati english speaking people" OR "tamil people" OR "british asian people" OR "gujarati people" OR "punjabi people" OR "bangladeshi people" OR "south asian people")
- S2 ti("mental health" OR "mental illness" OR disorder OR distress OR "mental N/3 service\*" OR "psycholog\* N/2 service\*" OR "primary care" OR "community mental" OR CMHT OR psychotherap\* OR therap\* OR counsel\*) OR ab("mental health" OR "mental illness" OR disorder OR distress OR "mental N/3 service\*" OR "psycholog\* N/2 service\*" OR "primary care" OR "community mental" OR CMHT OR psychotherap\* OR therap\* OR counsel\*) OR su("mental health" OR "mental health services" OR "mental health care" OR "primary health care" OR "community mental health services" OR "psychotherapy" OR "counselling")
- S3 ti(accept\* OR access\* OR barrier? OR challeng\* OR engag\* OR exclu\* OR hind\* OR limit\* OR obstacle? OR pathway? OR use OR utili\* OR "help?seeking" OR "seek\* N/3 help" OR "seek\* N/3 support") OR ab(accept\* OR access\* OR barrier? OR challeng\* OR engag\* OR exclu\* OR hind\* OR limit\* OR obstacle? OR pathway? OR use OR utili\* OR "help?seeking" OR "seek\* N/3 help" OR "seek\* N/3 support") OR su("help seeking behavior" OR "health services accessibility" OR "patient acceptance of health care" OR "quality of care" OR "quality of service")
- S4 qualitative OR interview\* OR "focus group\*" OR "content analysis" OR "discourse analysis" OR ethnograph\* OR "grounded theory" OR "mixed?method\*" OR narrative\* OR phenomenolog\* OR "thematic analysis"
- S5 Engl\* OR Scot\* OR Wales OR Welsh OR "Northern Ireland" OR "United Kingdom" OR UK OR "Great Britain" OR Brit\*
- S6 S1 AND S2 AND S3 AND S4 AND S5  
Applied filters – Publication date: 1999-01-01 - 2019-12-31

*Search results = 677*

*Search field codes:*

ti = Title

ab = Abstract

su = Subject heading (all)



## Appendix B – Critical Appraisal Skills Programme Qualitative Checklist

	Yes (2)	Can't tell (1)	No (0)
1. Was there a clear statement of the aims of the research?			
2. Is a qualitative methodology appropriate?			
3. Was the research design appropriate to address the aims of the research?			
4. Was the recruitment strategy appropriate to the aims of the research?			
5. Was the data collected in a way that addressed the research issue?			
6. Has the relationship between researcher and participants been adequately considered?			
7. Have ethical issues been taken into consideration?			
8. Was the data analysis sufficiently rigorous?			
9. Is there a clear statement of findings?			
10. How valuable is the research?			

## Appendix C – Ethical approval from Coventry University



### Certificate of Ethical Approval

Applicant:

Riddhi Parmar

Project Title:

A qualitative exploration of South Asian women's experiences of living with, and seeking help for, medically unexplained symptoms.

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Medium Risk

Date of approval:

14 May 2018

Project Reference Number:

P67638



## Medium to High Risk Research Ethics Approval

Project Title

**A qualitative exploration of South Asian women's experiences of living with, and seeking help for, medically unexplained symptoms.**

### Record of Approval

Principal Investigator

I request an ethics peer review and confirm that I have answered all relevant questions in this checklist honestly.	X
I confirm that I will carry out the project in the ways described in this checklist. I will immediately suspend research and request new ethical approval if the project subsequently changes the information I have given in this checklist.	X
I confirm that I, and all members of my research team (if any), have read and agreed to abide by the Code of Research Ethics issued by the relevant national learned society.	X
I confirm that I, and all members of my research team (if any), have read and agreed to abide by the University's Research Ethics, Governance and Integrity Framework.	X

Name: Riddhi Parmar.....

Date: 09/02/2018.....

#### Student's Supervisor (if applicable)

I have read this checklist and confirm that it covers all the ethical issues raised by this project fully and frankly. I also confirm that these issues have been discussed with the student and will continue to be reviewed in the course of supervision.

Name: Helen Lieblich.....

Date: 06/04/2018.....

#### Reviewer (if applicable)

Date of approval by anonymous reviewer: 11/05/2018

TO WHOM IT MAY CONCERN

QRS/Ethics/Sponsor/et

Monday, 14 May 2018

Dear Sir/Madam

**Researcher's name:** Riddhi Parmar


**Project Reference:** P67638

**Project Title:** A qualitative exploration of South Asian women's experiences of living with, and seeking help for, medically unexplained symptoms

The above named researcher has successfully completed the Coventry University Ethical Approval process and received authorisation for their project to proceed.

I should like to confirm that Coventry University is happy to act as the sole sponsor for this researcher and attach details of our Public Liability Insurance.

Yours faithfully



Olivier Sparagano

Associate Pro-Vice-Chancellor – Research

Enc

## Appendix D – Ethical approval from the Health Research Authority



Mrs Riddhi Prajapati  
Clinical Psychology Doctorate, School of Psychology and  
Behavioural Sciences  
Faculty of Health and Life Sciences, James Starley Building  
Coventry University, Priory Street, Coventry  
CV1 5FB

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)  
[Research-permissions@wales.nhs.uk](mailto:Research-permissions@wales.nhs.uk)

09 August 2018

Dear Mrs Prajapati

### **HRA and Health and Care Research Wales (HCRW) Approval Letter**

<b>Study title:</b>	<b>A qualitative exploration of South Asian women's experiences of living with and seeking help for medically unexplained symptoms.</b>
<b>IRAS project ID:</b>	<b>244179</b>
<b>Protocol number:</b>	<b>N/A</b>
<b>REC reference:</b>	<b>18/SW/0160</b>
<b>Sponsor</b>	<b>Coventry University</b>

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

#### **How should I continue to work with participating NHS organisations in England and Wales?**

You should now provide a copy of this letter to all participating NHS organisations in England and Wales, as well as any documentation that has been updated as a result of the assessment.

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the "*summary of assessment*" section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

## Appendix E – Ethical approval from Research & Development departments



Wednesday, 14 November 2018

Research and Innovation Department  
Birmingham Community Healthcare  
NHS Foundation Trust  
3 Priestley Wharf  
Holt Street  
Aston  
Birmingham B7 4BN

Tel: 0121 466 7078

Email: [research.innovation@bhamcommunity.nhs.uk](mailto:research.innovation@bhamcommunity.nhs.uk)

**From:** Research and Innovation on behalf of Human Resources Directorate

Dear Mrs Riddhi Prajapati,

### Letter of Access for NHS Researcher

This Letter of Access for NHS Researchers has been issued by Birmingham Community Healthcare NHS Foundation Trust to enable you to undertake the following research within this organisation:

<b>Research Title:</b>	South Asian women's experiences of medically unexplained symptoms
<b>BCHC Ref.:</b>	BCHCASR244179.Portfolio
<b>Local Research Manager:</b>	Dr Adam Cleary
<b>Researcher's Substantive Employer:</b>	Coventry and Warwickshire Partnership Trust

In accepting this letter, Birmingham Community Healthcare Foundation NHS Trust confirms your right of access to conduct this research through the organisation for the purpose and on the terms and conditions set out below:

1. You have a right of access to conduct the above mentioned research.
2. The research should not commence until it has received NHS Permission from the Trust's Research and Innovation Team.
3. This letter should be presented before you commence your research within this Trust.

Research in the NHS: HR Good Practice Resource Pack, L003 - Example NHS to NHS letter of access for NH researchers who have a substantive NHS contract of employment with the organisation or clinical academics with an honorary clinical contract with an NHS organisation, Version 2.3, August 2013

BCHC Version 1, 10.07.2015

Page 1 of 3





14<sup>th</sup> December 2018

**Private and Confidential**

**Mrs Riddhi Prajapati**  
**Trainee Clinical Psychologist**  
**c/o Psychological Services,**  
**The Pines,**  
**St. Michael's Hospital,**  
**Warwick, CV34 5QW**

Dear Mrs Prajapati

**RE: Letter of Access for Research – A qualitative exploration of South Asian women's experiences of living with and seeking help for medically unexplained symptoms**

This letter confirms your right of access to conduct research through Leicestershire Partnership NHS Trust for the purpose and on the terms and conditions set out below. This right of access commences on **14<sup>th</sup> December 2018** and ends on **27<sup>th</sup> September 2019** unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation (and as detailed in the research passport application). Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

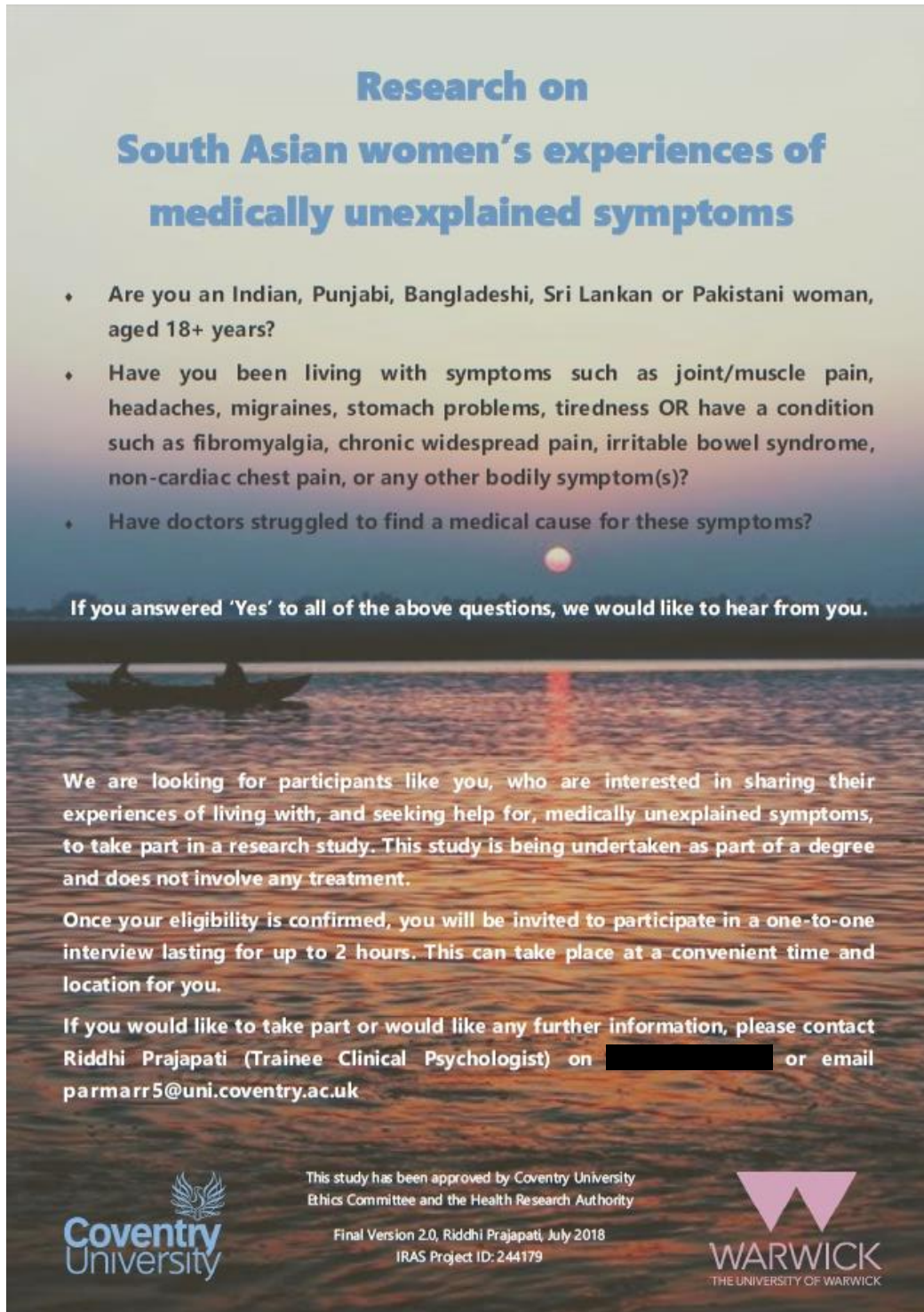
The information supplied about your role in research at Leicestershire Partnership NHS Trust has been reviewed and you do not require an honorary research contract with this NHS organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to Leicestershire Partnership NHS Trust premises. You are not entitled to any form of payment or access to other benefits provided by this NHS organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through Leicestershire Partnership NHS Trust, you will remain accountable to your employer the University of York but you are required to follow the reasonable instructions of **Dr Dave Clarke, Research and Development Operational Lead** and to liaise with **Dr**



## Appendix F – Recruitment Poster



### Research on South Asian women's experiences of medically unexplained symptoms


- Are you an Indian, Punjabi, Bangladeshi, Sri Lankan or Pakistani woman, aged 18+ years?
- Have you been living with symptoms such as joint/muscle pain, headaches, migraines, stomach problems, tiredness OR have a condition such as fibromyalgia, chronic widespread pain, irritable bowel syndrome, non-cardiac chest pain, or any other bodily symptom(s)?
- Have doctors struggled to find a medical cause for these symptoms?

If you answered 'Yes' to all of the above questions, we would like to hear from you.

We are looking for participants like you, who are interested in sharing their experiences of living with, and seeking help for, medically unexplained symptoms, to take part in a research study. This study is being undertaken as part of a degree and does not involve any treatment.


Once your eligibility is confirmed, you will be invited to participate in a one-to-one interview lasting for up to 2 hours. This can take place at a convenient time and location for you.

If you would like to take part or would like any further information, please contact Riddhi Prajapati (Trainee Clinical Psychologist) on [REDACTED] or email [parmarr5@uni.coventry.ac.uk](mailto:parmarr5@uni.coventry.ac.uk)

 Coventry University

This study has been approved by Coventry University Ethics Committee and the Health Research Authority

Final Version 2.0, Riddhi Prajapati, July 2018  
IRAS Project ID: 244179

 WARWICK  
THE UNIVERSITY OF WARWICK



## **Appendix G – Participant Information Sheet**

You are being invited to take part in research on how South Asian women make sense of living with medically unexplained symptoms, and experience seeking help or support for these symptoms. Riddhi Prajapati, Trainee Clinical Psychologist at Coventry University is leading this research as part of a Doctoral degree in Clinical Psychology. Before you decide to take part it is important you understand why the research is being conducted and what it will involve. Please take time to read the following information carefully.

### **What is the purpose of the study?**

This research aims to explore how South Asian women make sense of living with medically unexplained symptoms, and experience seeking help or support for these symptoms.

Medically unexplained symptoms are bodily symptoms which affect many people and persist over time, but have no identifiable organic cause. These can include muscle or joint pain, headaches, digestion problems or tiredness. Certain patterns of symptoms are often described as conditions such as irritable bowel syndrome, chronic widespread pain, fibromyalgia, or non-epileptic attack disorder.

### **Why have I been chosen to take part?**

You are invited to participate in this study as you have been identified as a South Asian woman who may be living with one or more of the symptoms or conditions described above.

### **What will happen if I decide to take part?**

Your participation in this study will involve a one-to-one interview with the Lead Researcher, which should take around 1-2 hours to complete. The interview will take place in a safe environment, which could include your home if this is felt most comfortable, and at a time that is convenient for you.

Before the interview starts, you will be asked to sign a Consent Form and complete some questionnaires, related to your thoughts about your symptoms, and the impact of your symptoms on your mood and daily functioning.

The interview will invite you to share your experiences of living with medically unexplained symptoms, as well as your experiences of seeking help and support to manage or treat these symptoms. Ideally, we would like to record the interview on an audio device.

At the end of the interview, you will be debriefed and will have the opportunity to ask questions. You will also have the option of receiving a summary of the main findings of this research, to have an opportunity to share any feedback or comments. You can indicate whether or not you would like to receive this summary on the Consent Form before the interview.

**What are the possible benefits of taking part?**

It is hoped that your participation in this research will give you an opportunity to share your experiences of living with and managing medically unexplained symptoms, which may help health services to better understand the needs of South Asian women. It is also hoped that your data will be used in the production of formal research outputs e.g. conference papers, journal articles, theses and reports. Quotes or key findings will always be made anonymous in any formal outputs.

**What are the possible risks of taking part?**

There are no significant risks associated with participation. However, talking about your experiences of your symptoms may bring up a number of emotions and memories. If you share something that is difficult for you, this will be treated in confidence. However, if you or someone you know is in a vulnerable situation or at risk of harm, this may be shared with the research team and/or other agencies where appropriate. If you feel upset or concerned following your participation, you will be encouraged to contact your GP in the first instance. A list of support services and their contact details will also be provided following the interview.

**Do I have to take part?**

No, participation is entirely voluntary. You are free to withdraw your information from the study up to 2 weeks after the interview has taken place, without needing to give a reason. After this date, the data you provide will be fully anonymised on our records. To withdraw, please contact the Lead Researcher, as well as the Faculty Research Support Office, so that your request can be dealt with promptly in the event of the Lead Researcher's absence (contact details are on the next page). A decision to withdraw will not affect you in any way.

**What will happen to my data if I take part?**

This study has been reviewed and approved by Coventry University Ethics Committee and the Health Research Authority.

Coventry University is the sponsor for this study based in the UK. We will act as a Data Controller for the information you provide. This means that we are responsible for looking after your information and using it properly. Coventry University will keep identifiable information about you for 5 years after the study has finished. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible. You can find out more about how we use your information at [www.ico.org.uk](http://www.ico.org.uk) and/or by contacting the University Data Protection Officer at [enquiry.ipu@coventry.ac.uk](mailto:enquiry.ipu@coventry.ac.uk).

Your data will be processed in accordance with the General Data Protection Regulation (GDPR) 2018. All information collected about you will be kept strictly confidential and will be referred to by a pseudonym in our records, rather than by name. If you consent to being audio-recorded, all recordings will be destroyed once they have been transcribed. Your data will only be viewed by the Lead Researcher and Research team. All electronic data will be stored on a password-protected computer file on a password-protected storage disk, solely accessible by the Lead Researcher. All paper records will be stored in a locked cabinet at the Lead Researcher's home during the study, and in a locked filing cabinet at Coventry

University after the study has finished. Your consent information will be kept separately from your responses in order to minimise risk in the event of a data breach. The Lead Researcher will destroy all collected data within 5 years in line with Coventry University's policy.

NHS services will collect information from you and/or your medical records for this research study in accordance with our instructions. NHS services will keep your name and contact details confidential and will not pass this information to Coventry University. NHS services will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from Coventry University and regulatory organisations may look at your medical and research records to check the accuracy of the research study. Coventry University will only receive information without any identifiable information. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

In circumstances where the Lead Researcher feels that information you provide poses a risk to yourself or others, they will share this information with the research team and/or other agencies where appropriate.

#### **What if there is a problem?**

If you are unhappy with any aspect of the research, please first contact the Lead Researcher, Riddhi Prajapati. If you still have concerns or wish to make a formal complaint, please contact:

Professor Olivier Sparagano

University Applied Research Committee, Coventry University, Priory Street, Coventry, CV1 5FB

Email: [REDACTED]

#### **What do I do now?**

If you have any further questions before deciding whether or not you would like to participate, please contact the Lead Researcher. If you decide that you would like to take part, please contact the Lead Researcher, Riddhi Prajapati, to register your interest. If you decide that you do not want to take part, you do not need to take any further action.

**Research team contact details:**

Riddhi Prajapati

*Lead Researcher*

Trainee Clinical Psychologist

Coventry University

parmarr5@uni.coventry.ac.uk

[REDACTED]

Dr Helen Liebling

*Academic Supervisor*

Assistant Professor in Clinical Psychology

Coventry University

hsx497@coventry.ac.uk

[REDACTED]

Dr Adam Cleary

*Clinical Supervisor*

Consultant Clinical Psychologist

Birmingham Community Healthcare NHS Trust

adam.cleary@bhamcommunity.nhs.uk

[REDACTED]

Faculty of Health and Life Sciences, Research Support Office, Coventry University

ethics.hls@coventry.ac.uk

[REDACTED]

## Appendix H – Consent Form

You have been invited to take part in this research study for the purposes of collecting data on how South Asian women make sense of living with medically unexplained symptoms, and experience seeking help or support for these symptoms.

Before you decide to take part, please read the Participant Information Sheet. Please do not hesitate to ask questions if anything is unclear or if you would like more information about any aspect of this research. It is important that you feel able to take the necessary time to decide whether or not you wish to take part.

**If you are happy to participate, please confirm your consent by circling 'Yes' against each of the statements below, and then signing and dating the form as Participant.**

1.	I confirm that I have read and understood the Participant Information Sheet for the above study and have had the opportunity to ask questions.	Yes	No
2.	I understand that my participation is entirely voluntary and that I am free to withdraw my data up to 2 weeks after the interview has taken place, by contacting the Lead Researcher and Faculty Research Support Office, without giving a reason.	Yes	No
3.	I am happy for the interview to be audio-recorded. I understand that all recordings will be deleted once transcribed.	Yes	No
4.	I understand that all the information I provide will be held securely and treated confidentially, in accordance with the General Data Protection Regulation (2018).	Yes	No
5.	I understand that if I share sensitive information regarding a potential to harm myself or others, the Lead Researcher may discuss this with the research team to decide upon the appropriate action and support.	Yes	No
6.	I understand that if I lose the capacity to consent after participating, the transcribed data already collected will be retained for use in the study.	Yes	No
7.	I am happy for the information I provide to be used anonymously in academic papers and other formal research outputs.	Yes	No
8.	I understand that I can contact the Researchers if I would like more information about the study, if anything is not clear, or if I experience distress following my participation and would like advice or support.	Yes	No
9.	I would like the Researcher to send me a written summary of the main findings of the above study, and to contact me to discuss whether the findings reflect the experiences I share in the interview.	Yes	No
10.	I agree to take part in the above study.	Yes	No

**Thank you for your participation in this study. Your help is very much appreciated.**

Participant's name: .....

Signature: ..... Date: .....

Researcher's name: .....

Signature: ..... Date: .....

## Appendix I – Demographic Questionnaire

We would appreciate if you could answer the following questions, to give us more information about the experiences of participants in this research study.

### Questions about you

---

1. What is your age? .....
2. Where were you born? .....
3. If born outside the UK, when did you move to the UK? .....
4. Which South Asian ethnic group do you belong to?
  - ☐ Indian
  - ☐ Pakistani
  - ☐ Bangladeshi
  - ☐ Other (please specify) .....
5. What language(s) do you speak?

<input type="checkbox"/> English	<input type="checkbox"/> Tamil
<input type="checkbox"/> Hindi	<input type="checkbox"/> Punjabi
<input type="checkbox"/> Gujarati	<input type="checkbox"/> Urdu
<input type="checkbox"/> Bengali	<input type="checkbox"/> Other (please specify)
<input type="checkbox"/> Marathi	.....
6. Which religious denomination do you belong to (if any)?

<input type="checkbox"/> Hinduism	<input type="checkbox"/> Buddhism
<input type="checkbox"/> Jainism	<input type="checkbox"/> Baha'i
<input type="checkbox"/> Sikhism	<input type="checkbox"/> Other (please specify)
<input type="checkbox"/> Islam	.....
<input type="checkbox"/> Christianity	<input type="checkbox"/> Prefer not to say
7. What is your highest level of education? .....
8. What is your main occupation? .....

## Questions about your symptoms

---

9. Which of the following conditions have you been diagnosed with (if any)?  
(Please tick as many that apply to you)

- |  |  |
|--|--|
| <input type="checkbox"/> Chronic widespread pain       | <input type="checkbox"/> Non-epileptic attack disorder |
| <input type="checkbox"/> Chronic pelvic pain           | <input type="checkbox"/> Hyperventilation              |
| <input type="checkbox"/> Non-cardiac chest pain        | <input type="checkbox"/> Multiple chemical sensitivity |
| <input type="checkbox"/> Irritable bowel syndrome      | <input type="checkbox"/> Functional dyspraxia          |
| <input type="checkbox"/> Chronic fatigue syndrome / ME | <input type="checkbox"/> Other (please specify)        |
| <input type="checkbox"/> Fibromyalgia                  | .....  |

10. Which of the following symptoms have you experienced persistently for 3+ months?  
(Please tick as many that apply to you)

- |   |   |
|---|---|
| <input type="checkbox"/> Pains in the muscles | <input type="checkbox"/> Insomnia               |
| <input type="checkbox"/> Pains in the joints  | <input type="checkbox"/> Nausea                 |
| <input type="checkbox"/> Back pain            | <input type="checkbox"/> Bloating               |
| <input type="checkbox"/> Chest pain           | <input type="checkbox"/> Constipation           |
| <input type="checkbox"/> Heart palpitations   | <input type="checkbox"/> Diarrhoea              |
| <input type="checkbox"/> Headaches            | <input type="checkbox"/> Abdominal pain         |
| <input type="checkbox"/> Fatigue              | <input type="checkbox"/> Shortness of breath    |
| <input type="checkbox"/> Dizziness            | <input type="checkbox"/> Other (please specify) |
| <input type="checkbox"/> Blurred vision       | .....   |

11. When were your symptoms first medically investigated?.....

12. When were your symptoms last medically investigated? .....

13. Which medical healthcare professionals/services have been involved in your care relating to these symptoms (if any)?

(Please tick as many that apply to you)

- |   |   |
|---|---|
| <input type="checkbox"/> General Practitioner | <input type="checkbox"/> Cardiologist           |
| <input type="checkbox"/> Gastroenterologist   | <input type="checkbox"/> Neurologist            |
| <input type="checkbox"/> Rheumatologist       | <input type="checkbox"/> Physiotherapist        |
| <input type="checkbox"/> Endocrinologist      | <input type="checkbox"/> Other (please specify) |
| <input type="checkbox"/> Pain Clinic          | .....   |

14. Which mental healthcare professionals/services have been involved in your care relating to these symptoms (if any)?

(Please tick as many that apply to you)

- |  |   |
|--|---|
| <input type="checkbox"/> Counsellor            | <input type="checkbox"/> Improving Access to Psychological Therapies (IAPT) |
| <input type="checkbox"/> Clinical Psychologist | <input type="checkbox"/> Community Mental Health Team                       |
| <input type="checkbox"/> Psychotherapist       | <input type="checkbox"/> Individual/group therapy                           |
| <input type="checkbox"/> Mental Health Nurse   | <input type="checkbox"/> Other (please specify)                             |
| <input type="checkbox"/> Psychiatrist          | .....   |

## Appendix J – Interview Schedule

1. Could you tell me a bit about yourself?

### Living with your symptoms

---

1. Could you give me a brief history of your symptoms\* from when it/they started?
2. How would you describe your symptoms in your own words or culture?
3. How do you feel when you experience these symptoms?
4. How do/does [these symptoms] affect your everyday life?

### Making sense of your symptoms

---

5. Do you have any thoughts about why you have these symptoms?
  - Do you think these symptoms relate to your emotions or mental health? If so, how?
  - Do you think that stigma and shame is associated with having these symptoms? If so, how?
  - Do you think that South Asian\* culture is associated with these symptoms? If so, how?
6. What is it like being a South Asian woman and having symptoms that can't be medically explained?
  - Do you think that having these symptoms is different for South Asians, than for other ethnic groups? If so, how?
  - Do you think that having these symptoms is different for women? If so, how?
7. How do you cope with living with your symptoms in everyday life?
8. How have your family, friends and community responded to your symptoms?

### Experiences of seeking help/support

---

9. How have you found the treatment you've received from statutory services?
  - Were there any helpful experiences? If so, can you tell me more about them?
  - Were there any unhelpful experiences? If so, can you tell me more about them?
10. Have you sought help or support from any other services outside the NHS for your symptoms? If so:
  - What led you to seek support from these services?
  - How have you found the treatment you've received from these services?

### Suggestions for service delivery

---

11. What are your thoughts about how services are provided to investigate and manage MUS?
  12. Do you think that statutory services could be improved for South Asian women with MUS? If so, how?
  13. Is there anything else you would like to tell me about before we finish?
- How do you feel after answering these questions?
- Are you feeling upset, unhappy or concerned about anything that we have talked about?

\*or preferred term for the participant



## Appendix K – Guide for Managing Risk

To be used under the following circumstances:

- If the participant expresses any distress during the interview
- If the participant raises concern in relation to themselves/someone else being at risk of harm
- If the participants' responses to the study questionnaires indicate severe distress in relation to their symptoms

### Protocol

---

1. Pause the interview and explore the concerns
2. If the participant expresses intent to harm themselves or someone else, establish the frequency, intensity, and duration of these thoughts
3. Explain that you will ask some questions about their thoughts:
  - Have you made a plan?
  - What is that plan?
  - Do you have everything you need to carry out your plan?
  - Is there anything stopping you from carrying out your plan?
  - What helps you to feel safe? (protective factors)
  - Have you spoken to anyone about the way you've been feeling?
  - If no, is there someone you feel you could talk to? What's stopping you from talking to them?
4. Establish whether the participant is currently under mental health care (i.e. has a named clinician or access to crisis support)
5. Follow protocol in the table overleaf to decide on an appropriate response.

Degree of risk	Researchers' response
<b>Mild</b> <ul style="list-style-type: none"> <li>Thoughts to harm self/other are of limited frequency, intensity and duration</li> <li>No plans or intent</li> <li>Identifiable protective factors.</li> </ul>	<ol style="list-style-type: none"> <li>Offer participant list of <i>Support Services</i></li> <li>Ask them to seek immediate assistance if their thoughts become more serious.</li> <li>If they are able and willing to continue, offer a break and resume the interview.</li> </ol>
<b>Moderate</b> <ul style="list-style-type: none"> <li>Thoughts to harm self/other are of limited frequency, intensity and duration</li> <li>Some plans but no intent (or some intent but no plans)</li> <li>Some risk factors present, but also some protective factors.</li> </ul>	<ol style="list-style-type: none"> <li>Offer participant list of <i>Support Services</i></li> <li>Ask them to seek immediate assistance if their thoughts become more serious</li> <li>Offer to assist in arranging an appointment</li> <li>Discuss with research supervisor(s) if unsure.</li> <li>If they are able and willing to continue, offer a break and resume the interview.</li> </ol>
<b>Severe</b> <ul style="list-style-type: none"> <li>Thoughts to harm self/other are frequent, intense and enduring</li> <li>Specific plans, some intent, method is available/accessible</li> <li>Multiple risk factors and few protective factors.</li> </ul>	<ol style="list-style-type: none"> <li>Stop the interview</li> <li>Tell the participant that you're concerned and that you may need to speak to your supervisor(s)</li> <li>Contact research supervisor(s) and provide information about your concerns: <ul style="list-style-type: none"> <li>Decide if appropriate to contact relevant services to help protect the participant/others e.g. GP, crisis team, safeguarding</li> <li>Decide whether to ask the participant to contact you (or you contact them) at a specific time.</li> </ul> </li> <li>If they are able and willing to continue participating in the research study, offer them the opportunity to re-arrange the interview for another time.</li> </ol>
<b>Extreme</b> <ul style="list-style-type: none"> <li>Thoughts to harm self/other are frequent, intense and enduring</li> <li>Clear plans and intent, method is available/accessible</li> <li>Multiple risk factors and no protective factors.</li> </ul>	<ol style="list-style-type: none"> <li>Stop the interview</li> <li>Tell the participant that you're concerned and that you will need to speak to your supervisor(s)</li> <li>Contact research supervisor(s) and provide information about your concerns: <ul style="list-style-type: none"> <li>Decide if appropriate to contact relevant services to help protect the participant/others e.g. GP, crisis team, safeguarding</li> <li>Decide whether to ask the participant to contact you (or you contact them) at a specific time.</li> </ul> </li> <li>If they are able and willing to continue participating in the research study, offer them the opportunity to re-arrange the interview for another time.</li> </ol>

(adapted from the Protocol: Interviewer Safety Manual by UNSW Australia, 2015:  
[https://staff.med.unsw.edu.au/sites/default/files/\\_local\\_upload/Interviewer%20manual%20FINAL%20final%20ratified%20revision%202.1%20final.pdf](https://staff.med.unsw.edu.au/sites/default/files/_local_upload/Interviewer%20manual%20FINAL%20final%20ratified%20revision%202.1%20final.pdf))

## Appendix L – Debriefing Information Sheet

I appreciate the time that you have taken to share your experiences with me. I hope you have found some benefit in participating in this research, which hopes to improve our understanding of the unique experiences of South Asian women with medically unexplained symptoms. It is hoped that the findings of this research will improve the understanding of healthcare professionals, as well as inform service delivery and provision.

Talking about your experiences of painful symptoms can be difficult and may bring up a number of different emotions and memories. If you are feeling upset or concerned following your participation in this research you can contact your GP or Medical Consultant if you have one. A list of other support services and their contact details are also provided overleaf.

I would like to remind you that you have the right to withdraw your information from this research up to 2 weeks after today's date, without needing to give a reason. If you have any other questions or concerns that you would like to raise about your participation in this research, please contact a member of the research team below.

### Research team contact details:

Riddhi Prajapati  
*Lead Researcher*  
Trainee Clinical Psychologist  
Coventry University  
parmarr5@uni.coventry.ac.uk  
[REDACTED]

Dr Helen Liebling  
*Academic Supervisor*  
Assistant Professor in Clinical Psychology  
Coventry University  
hsx497@coventry.ac.uk  
[REDACTED]

Dr Adam Cleary  
*Clinical Supervisor*  
Consultant Clinical Psychologist  
Birmingham Community Healthcare NHS Trust  
adam.cleary@bhamcommunity.nhs.uk  
[REDACTED]

If you require further assistance or if there are any problems that cannot be resolved by the research team, please contact:

Faculty of Health and Life Sciences, Research Support Office, Coventry University  
ethics.hls@coventry.ac.uk  
[REDACTED]

## **Support Services**

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### **Sahil Project**

Sahil provides person-centred, mental health and wellbeing services for South Asian people across Coventry and Warwickshire. They also provide practical and emotional support, to build confidence, reduce social isolation and support an individual towards empowerment and recovery.

Phone: 02476 638 754

Email: [sahil.project@btopenworld.com](mailto:sahil.project@btopenworld.com)

### **Tamarind Centre**

The Tamarind Centre aims to provide support to the BAME (Black, Asian and Minority Ethnic) communities of Coventry who are experiencing mental ill-health. They provide a number of services, including mental health support, drop-in services, and counselling.

Phone: 02476 227 712 or 02476 225 512

Email: [info@tamarindcentre.co.uk](mailto:info@tamarindcentre.co.uk)

Web: <http://tamarindcentre.co.uk/index.html>

### **Adhar Project**

The Adhar Project empowers people from the BAME community in Leicester to take control of and manage their mental health difficulties. Their services include therapeutic support using arts, social and cultural activities delivered as individual support and group sessions, advocacy, and advice and information.

Phone: 0116 220 0070

Email: [admib.box@adharproject.org](mailto:admib.box@adharproject.org)

Web: <http://www.adharproject.org/>

### **The Black, African and Asian Therapy Network**

The BAATN support and encourage people of Black African, Asian and Caribbean heritage to engage proactively and consciously in their psychological lives. They offer a tool to search for therapists of Black and Asian backgrounds.

Email: [connect@baatn.org.uk](mailto:connect@baatn.org.uk)

Web: <https://www.baatn.org.uk/>

### **Muslim Women's Network**

The Muslim Women's Network provides a national specialist faith and culturally sensitive helpline service which offers information, support, guidance and referrals to Asian and Muslim women and girls from diverse ethnic/faith backgrounds who are suffering from or at risk of abuse or facing problems on a range of issues.

Phone: 0208 904 8193 or 0208 908 6715

Web: <http://www.mwnhelpline.co.uk/>

### **Mind – the mental health charity**

Phone: 0300 123 3393

Email: [infor@mind.org.uk](mailto:infor@mind.org.uk)

Web: <https://www.mind.org.uk/>

### **Samaritans**

Phone: 116 123

Email: [jo@samaritans.org](mailto:jo@samaritans.org)

Web: <https://www.samaritans.org/>

## Appendix M – Example of an annotated transcript for IPA

language barrier prevents adequate care

Searching for an explanation

multiple possible reasons

"Asian women are meek"

defensive practice from doctors?

repeatedly "fobbed off"

searching for an explanation

not treated equally by doctors

Fighting gets you results

Search failing over life

role reversal?  
language barrier interpreting for Mum – duty/responsibility?

questioning why Mum was dismissed  
combination of multiple factors?  
multiple truths?

'Asian women are meek'  
all doctors dismiss Asian women  
loss of previous role

doctors worried about patients fighting back?

doctors judge your job, not symptoms

repeatedly "fobbed off"  
dismissal prolongs diagnosis

questioning reasons for dismissal – there must be an explanation?

deserve equal service – treated differently? ANGER?

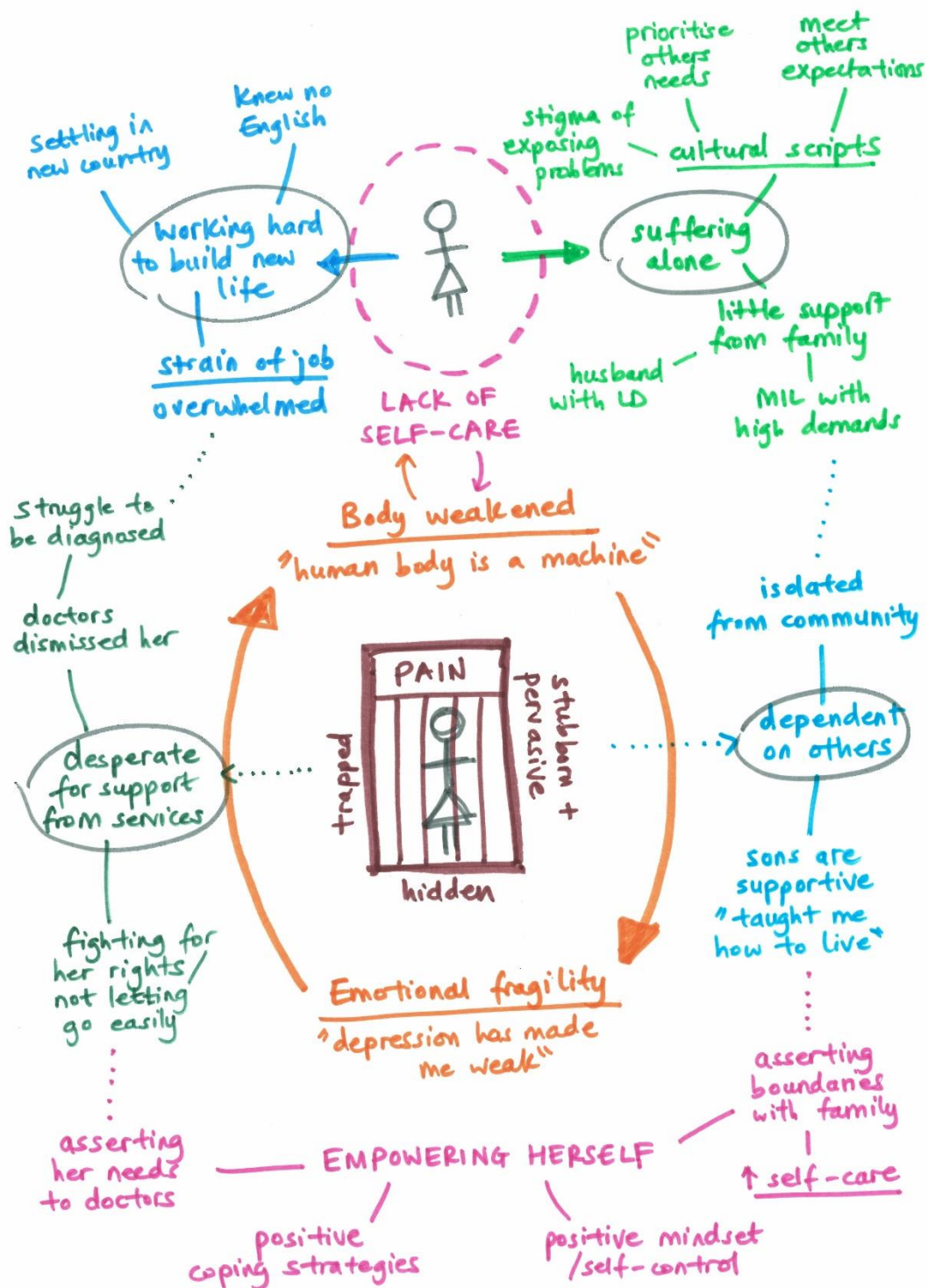
being obedient → dismissed  
"fighting back" → results

overwhelmed by appointments  
chaotic life?

HAD ENOUGH of inadequate explanations  
using own initiative

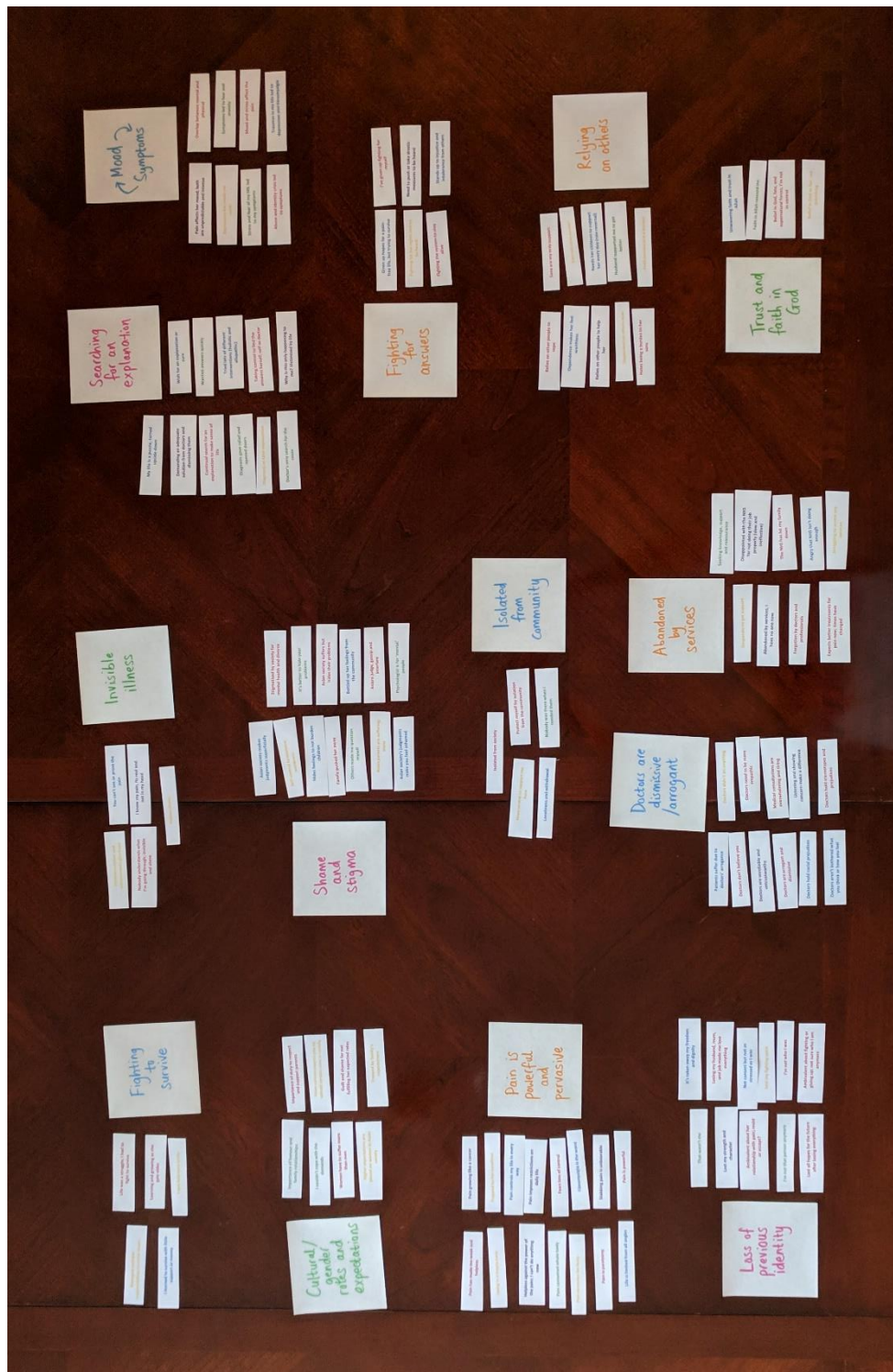
mum passed away at the age of 48. She had, uh, she had some heart problems, blood pressure problems and heart problems. I grew up, um, continuously, you know, going to the doctor's, interpreting for her. Her first language was Punjabi, she couldn't really speak English. And a lot of the time, even with myself, and when I think about it when I'm looking back, my mum was dismissed on a lot of her symptoms. Now (a) I don't know whether it's because she couldn't explain what's going on, (b) the language barrier, and (c) because she had a child interpreting for her. Do you know what I mean? So those three things combined together, I don't know whether they all kind of got together and you know, that's what led to her being dismissed. But what I do want to point out is that it's not oh, you know, the South Asian doctors understand South Asian women's issues, no, I, from my experience, and from family members experience, it doesn't matter what background the doctor is. I think Asian women in general, are seen as like, sort of the stereotypical view is they're quite meek. They're not very vocal. And you know, unless you're really vocal... I mean [sigh] I've had questions asked to me, "Oh so what do you do job wise?" When I said something like, "Oh, you know, which is my background, which is finance", you know what? I walked out of the door with an appointment to see a physiotherapist. Now, because I've got two small children, and I've had to go part-time, and I'm doing a little role in customer service, I've just been fobbed off with a prescription Zepain or antidepressants. Now I don't know whether they sort of think, right, maybe... I'm just speaking out loud, but what it really feels to me is, if you're in a certain criteria, then "Yeah, you know what? She might fight back. She might have a little bit of, you know, she might have something about her that she'll fight back. So you know what, let's take this down that lead." But I don't know whether they use your job to kind of assess where you are, rather than actually sitting down and exploring your symptoms. They try to find out where you are, are you somebody that you can fob off, or are you someone that's going to come back and fight with the system? Now with my own daughter, she's four years old, it's taken me three years to kind of get her to see a paediatrician. Because every time I've gone there, I've been ill myself, I've been dismissed, "No it's fine." And now she's severely underweight, and there's a possibility that she might have coeliac disease. So it's taken me three years to actually fight, and that's predominantly Asian doctors that I've been seeing, and just being fobbed off time and time... Now, I don't know whether that's just an Asian issue, or whether it's just a general mum issue, or whether they think "Will you keep going back?" I don't know. But I work, my husband works, we pay our taxes, we deserve that service. That's the way I see it. Even if you don't work and you're on benefits, you still deserve equal treatment. Do you know what I mean? To me, that really kind of gets to me. You know, if you're going to fight back, if you're going to be very vocal, "Yeah, we'll refer you." But if you're just going to sort of say, "Okay doctor", and put all your trust into that doctor, and be very obedient and listen to what they're saying, they are going to fob you off with antidepressants and Zepain and the highest dose of painkillers they can give you. Going back to my mum, I don't know, I've only now - this really winds me up - through occupational work, my workplace, they decided to do an occupational health check, because I had some time off. Then I was having appointments left, right and centre to say "You might have arthritis, you might have, you know, multiple sclerosis, let's get this checked out." So I'm going left and right to clinics and appointments for God knows how many years. And then I thought, you know, enough is enough. I went, I had a blood test done privately and they said, "Your thyroid is in a very high range." And it made sense. It clicked. When I went back to my GP, "Oh we'll put it down as sub-clinical." Do you know what I mean? You're putting me in a range from 1 to 10, my body, my anatomy, it's going to be different to a six foot two male. Do you know what I mean? How can you put me into that category of that range? Um, I've gone back home, I've looked at my results. There's been in 2016,

## Appendix N – Representation of themes for one participant





## Appendix O – Visual mapping of themes across participants



## Appendix P – Additional participant quotes

### *Fighting to survive through trauma*

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Thoughts are coming too, and everything about my past life, that what sort of person I was? Never depended on anybody, and never demanding to anybody, from my parents' house, I never been like that [sobbing]. For everyone, "It's fine, it's fine". I have learned but, too late, when I learned all these things, that it's not fine, you should demand, then only you get things in life, otherwise you don't get anything. But it's too late now, who shall I demand from, myself? (Jyoti: 873-880)

I used to be all over the place. Because constantly I'm thinking, "What do we do tomorrow, how do we eat, what are you doing?" I think the majority of people, especially in your research, majority of the people you will find, they have some kind of trauma like mine. Otherwise there wouldn't be any fibromyalgia, there wouldn't be any traumatic problems (in the body), because you fight for your life, and you fight to provide for your child. And you have to be their friend, their mum, their dad, their brother, their sister - everything, you have to be the only one. So my pain, I couldn't even say like one day I sleep through all night. (Nafisa: 244-250)

For Indian husbands, they would think "It's not my job. It's a woman's job, it's not my job." Make tea, it's not men's job, it's a woman's job. (Amna: 883-884)

In our generation and my previous generation, like my mother-in-law, they thinking daughter-in-law or vow or dikhri, they've got to, woman has got to cook and, cook - that's what they *should* do. Women *should* cook in the house, women should do housework, women should do this and that, everything women should be doing, not men. But they not thinking at the same time, because in this country, women *are* working same as men, so it should be equal, but it's not happening still... (Champa: 499-504)

I'll give you an example, I'll be washing some dishes and I'll regress. I'll go back to a traumatic time in my childhood. And then my little three year old will say "Mummy, mummy", to kind of get me back out of that. And I'm like, "What?", and I'm so engrossed in going back to that time and revisiting that pain, that I'm unaware of my surroundings. Do you know what I mean? So... And then I don't know, maybe after that I'll have an episode where my temples are really - like even today, like I've had a TMJ flare up, so my jaw is in extreme pain and my temples on the side of my head are really sore. Yeah, my neck pain is just chronic so I still can't move my neck. (Kiran: 900-907)

### *Powerless against the pain*

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You know, it's like a constant pain, like a shooting pain, because mine, it did start from the hip. Now, I'm having, in my knees now, because they told me that it affects the joints. And from like, uh, I think so it was, it's only one week, I'm having a problem in the left side now. It's like a painful, it's both legs now. And I find it difficult to walk as well. And it's like a, it comes from inside, the pain it comes from inside, you know, it's, it's from the bone, you know, like inside of the bone. That's why, you know, when they do the scan, they can't find nothing. It's from, you know like, it's a *sharp* pain, that you can't take it. (Sushila: 4-10)

I could just catch the bus from front of my door, and go to the shopping centre. But when I go there, I feel like, I cannot go through the escalator, I have to go by the lift. Because once upon a time, everything was like, not even thinking, I lived my life so freely, and now, I have to think, plan ahead... (Nafisa: 103-107)

Financially I've gone, you know, I'm on a downward slope. I've had to cut down a full-time job to a part-time job. Um, because I can't deal with it. You know, they expect budget sheets the next day, yet I can't get out of bed. (Kiran: 307-309)



If I need to get like dhana (coriander) and things like that, I'll get it. But if I had to get potatoes or onions, I have to ask my husband or my boys to get it for us...all physical stuff, I'm dependent on my husband and my boys. (Champa: 281-286)

Because what I hate, I've been an independent person all these years and now I'm not. Lots of things I have to depend on children as well. And I feel like it's not worth it for me to live like this. (Jyoti: 437-439)

### ***Shame, stigma and isolation***

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Because it is a disability and its unseen, that you know... If it was visible and I was in a wheelchair, people's approach to me would be a lot different...And then I feel kind of like, "Oh gosh I'm holding up the queue at school, I need to hurry up." And then that in itself causes me anxiety. And then on top of that I'm, you know, having a palpitation, in sort of a panicky state, that I need to hurry up. But then at the same time I'm in chronic pain because I'm trying to move and it's just not happening. You know? (Kiran: 503-506)

It is, it is. A lot different. Because usually women don't show much and they, cope more...And men, even if they sneeze, then they're poorly, and the women suffers a lot, still it doesn't matter, "You're a woman, so you have to put up with it". (Jyoti: 346-348)

The only reason I go to it, is because I feel shame, you know, to be the one, "Oh look, she didn't come because she didn't want to buy him a present" or "She just doesn't want to engage with us." I don't, I make no effort with my husband's side of the family, unless they've got a birthday party or an engagement party or something like that - that's the only time I'll go. Then I'll make the effort, because I haven't got the energy. I'd rather reserve that energy to make sure I've got enough energy to make sure I can read a book to my child at night-time, or wash their clothes or do something. (Kiran: 242-249)

But you know, they think I'm mental, I have gone mental [sobbing] I have got depression, everybody has depression now these days. But they think I have lost my plot completely, I haven't lost it, but they, they think... [sobbing] And some days when I'm on too much deep, I think I, yes, I have lost my plot. I'm not the same person [crying] this has changed my life completely. (Jyoti: 313-317)

Because I think people look at you different way as well, than normal people. "Oh, what's happened to you?", "Oh, okay". And then, as soon as they turn around, "Look what happened to her, look what she's got." (Jyoti: 646-648)

With South Asians, there's a lot of stigma attached with disability, and there's a lot of stigma attached to mental health, being mentally unwell. And people don't want to discuss it. That's what it is. People just don't want to say that "Yeah, my son has depression and you know, unfortunately we stopped him from committing suicide two nights ago." No, no, no, no, no. We just want to make out to the world that everything's *perfect*. You know, because God forbid somebody knows that something's not right in your family. People really need to kind of let go of those old ways of thinking, and just kind of give help to the people that need it....there's a lot of hush hush around the South Asian culture. A lot of things are silenced, a lot of things are just frowned upon, especially when it comes to mental health and any type of physical ailment. (Kiran: 731-743)

### ***Dismissed and alienated by professionals***

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I think I had depression and fibromyalgia at a similar time. But nobody recognised, I was *crying* to all the doctors, asking them, telling them, explaining to them, "Oh that's nothing. It's just what you been going through, because you're not sleeping enough." (Nafisa: 343-345)

I feel like sometimes they use, just because they're a doctor, they're using their harshness because of that. This is how I feel like, like 'I know better than you'... Obviously they know, they are the professionals. But I find it very, very difficult like... The way I'm talking to them, I wouldn't say they were actually interested in you. And they always say like, "Oh you have to go to your specialist." "You are my GP! What's happening? Can I not come to you?" You understand that? And they will say, "It's your fibromyalgia, what can I do? What else? I cannot do anything." I find it very rude. Their words are quite strong, I find it very, very rude sometimes. (Nafisa: 772-778)

Yeah, we just go there and... "Okay, go and do blood tests. The medication is right and we will see you in six months' time. That's it, is only the answer." You want the answer that 'why it's getting me another leg or another arm?' (Sushila: 602-609)

Oh, NHS [sigh] is like the worst. If you don't push, they don't care about you. You know, like they just want to kick you out...When you're in the hospital, and they want to discharge you quickly, because they want the bed, but they don't think like, this human being has got pain. You know, they don't think about the patient, they just want the bed, to come another people and kick out. That's, you know like, is the worst. I tell you honest, to have treatment with NHS, you need to be bad. You need to be shouting to them to give you the right medication. (Sushila: 575-582)

It's just, you know, it's that dismissive attitude of the GP of not wanting to investigate further. Not listening to the patient, do you know what I mean? Not listening. Just trying to think that they know better. You know? (Kiran: 633-635)

But if we're talking about *my* experience, it is, it's going to be the same story in a lot of those households. That you're going to get a lot of females my age who (a) probably aren't able to articulate what their actual symptoms are, and (b) you know, because of what's happened as they're growing up, they've become isolated, secluded, and they're just living with the chronic pain. And see, they're just really submissive and obedient to what the GP's saying. "Take the antidepressants, ignore the pain, there's nothing else wrong with you, it's your mind." Do you know what I mean? (Kiran: 658-664)

And then if you ask to be put through to a specialist, some doctors take it really badly, because they think, "Oh no, I'm the GP. I should be able to help you with this. No, no, let me go through it." So you're waiting another 6, 7, 8, 9, 10, 12 months before they actually decide and your symptoms have got worse, and then at that point they decide to kind of refer you to a specialist. (Kiran: 878-882)

### ***Struggling to find explanations***

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Because one thing is, 'cause it's your machine, you've got to put proper, you have to fill it with petrol, which we do, when we eat. But at the same time, it has to have some oil, filter, whatever else, service, body, whatever else it needs, you have to do that too. Because you did eat, to fill your belly, but you did not maintain whatever needed. Just like, you know, then that's the way my doctor explained it to me, and I did believe him... Because it's the human body you have, if you look after it like it's human, then everything will be fine...But it's just, the machine has become worn from inside, and you cannot replace those parts, that's it. You've got to live with it. (Champa: 472-482)

But I think it must have been meant in my life to change, because I think I never was going to give up my job. Since I was 15 year old, till just over 6 years ago I was working. I think probably God made me give up the job this way. That "sit down now, you've done enough work." Because I thought I'll work 10-15 years for myself before I retire, and after when I'm retired, I can enjoy my retirement. Probably kudrati, you know, that God said... "Don't think too far ahead, sit down at home." (Jyoti: 649-653)

You know, I can't say it's karma, because people they say its karma. But, okay, if its karma, I think so if its karma, then it should be certain, yes, which one I should have this kind of pain, then come back to my normal. I think like this, if it's karma... But, some people they say the karma, you know like, uh, they think that you need to have a pain for life, you know like, maybe you've done something and, you know like, those kind of things. I don't believe... I say, you know, I just believe if its karma, then it should be bad days and nice days as well, not always bad days... (Sushila: 419-424)

So that's now making me think, maybe I shouldn't just speak to one GP. Maybe I should go to five or six GPs. Do you know what I mean? And maybe rather than, you know... I work, I pay tax, my husband works, he pays tax - maybe now we should think about getting some private health care cover in place, because you know, we're not getting the answers we need from our GPs. (Kiran: 641-644)

### ***Navigating resilience and support***

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Then my children will say, "You know what, no memory lane. You stop mum, that's it, you don't need to talk about that. It's alright, we've come in okay." Especially with so less money, and then juggling with them. Um, my middle son was saying even last night, "Mum, apart from some of the things...you gave us wonderful childhood. We cooked with you, we danced with you, you know, we do Namaaz (prayer) together." (Nafisa: 871-877)

That's why I felt, I was kind of blaming myself as well. My husband said as well, "No, you're not blaming yourself." Even he understood that no, that's the way she's behaving and that's where it's affecting you, and nothing to blame yourself there...And I used to pick up the phone and the only person I could talk to was my husband. So I used to phone him every day and tell him these things. (Amna: 212-224)

Yeah, because I know 100%, I bet my life on it, Allah is always there, He *will* protect me, He will take care, you know, He *will* find a route for me...My shoulder, look at that, Allah put the army for me. This is Allah's army isn't it? I've got five children, they're my army and look, I have six grandchildren. Even they're little, when they're little, they started doing caring for me. (Nafisa: 671-676)

I just take the day comes. I wake up in the morning, and I just think for this day, I don't think for tomorrow, because, I don't know. And I just decide, you know like, I will take the day as it comes. There will be days which are I can't cope, and I don't know, maybe I can do something stupid, I don't know. Then I told my husband as well, I just want to go the, you know, it comes the day, finish the day, go to sleep. Not thinking about tomorrow. Because you know like, the more you think, the more you get frustrated. (Sushila: 476-481)

But, uh, I'm not feeling those, I'm not getting that emotional now, because obviously I have come out of it. If you had come that time, you would have seen me all, I'm going, you know. But you just have to make yourself strong from this. You just have to be brave and that's it, and that's what I've learned. (Amna: 985-988)

God is there, I do believe that. He is somewhere there, he's looking after us. I know...He is looking after us, so I still have so many positives...within me, within my thoughts. That's why I'm alive, otherwise I would have ended my life from ages ago. (Champa: 569-572)

## **Appendix Q – Clinical recommendations from participants**

### **More empathy, attentiveness and willingness to explore their concerns**

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Because, one thing, I want the NHS to know, that patient with the pain, first they need to understand the patient. If the patient tells you something, they should listen, not cut in the middle. And, they are doctors, they are trained, they know when the patient tells something, they know how to treat. But there is a, you know, there is a doctor, they don't want listen to you. They don't. (Sushila: 662-666)

I think (1) the doctors have to show a little empathy. They need empathy. (2) not to kind of, um, just kind of dismiss what the person's telling you about their symptoms. Um... you know and, (3) you know that sort of mental counselling type of, um, therapies, letting the patients know more about them. Yeah. Um... And just kind of, um, learning, knowing, and trying to read between the lines. (Kiran: 918-922)

There's no sympathy, no... Even if they explained to you, "Look, this is what's happening in your body." But no. I find it very, very difficult. And especially, because I understand and I speak English quite okay, I understand how they're saying to me, and sometimes I feel like they've been emotionless. Do you understand that? If I cry to you and if you don't have (any emotions)... They don't say, "This is what's happening to you", explaining - if they explained to you... Because sometimes I go mad if I don't sleep for several days. I go like really, really dark. I just couldn't, my head is hurting. This is what happens to me continuously. Then I'll go, and I will say this is the condition I'm having at the moment. And they all will just listen, and they will say like "Wahh" (no response). I feel like sometimes they use, just because they're a doctor, they're using their harshness because of that. This is how I feel like, like 'I know better than you'... Obviously they know, they are the professionals. But obviously, I find it very, very difficult like... The way I'm talking to them, I wouldn't say they were actually interested in you. And they always say like, "Oh you have to go to your specialist." "You are my GP! What's happening? Can I not come to you?" And they will say, "It's your fibromyalgia, what can I do? What else? I cannot do anything." I find it very rude. Their words are quite strong, I find it very, very rude sometimes. (Nafisa: 764-778)

I know there's an issue with resources and whatnot, but just take that time out to ask questions. Don't just superficially just look at the outer symptoms. Try to understand what the cause is. And if you disagree with another doctor, let the patient know where they stand. What options do the patients have? Do they, you know, because that patient is going to say, "Okay right, you're telling me this, he's telling me that. So from my understanding and my feelings, or you know, on his, I want to follow this particular route." You know, giving the patient the options to kind of manage their conditions, but also to choose which kind of line of investigation they want to go towards, do you know what I mean? (Kiran: 926-933)

### **Simplify medical terminology**

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There's a language barrier a lot for us...Because a lot of our Asians, even English people I'm sure, not everybody's that much educated...They can keep big word, but if they can explain it in smaller version, like what it is, then I think it's better for us to understand it. (Jyoti: 1068-1071)

### **Early diagnosis**

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They do need to do so much differently. Like, have a early diagnosis, whatever the situation is. Then people don't get into depression. Early diagnosis and get appropriate support. I know they're saying that it's not got a cure, but if you get a right support, then you would not get into the situation where I am at the minute (Champa: 781-784)

### **Better communication between different teams and professionals**

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That's things which one the NHS, they need to have, like...they need to know what another doctor they are telling, and they need to have a kind of communication. Because if they've got my NHS number, you know...They should have understanding with each doctor. Like the psychiatrist, before she discharged me, she could talk to the psychologist and ask "What is um, what do you think that Sushila needs to do? Or still you are going to give a session, or not?" But they didn't. I am out now. If anything happens to me, I need to go through again to the GP. That's why I'm telling you, you remember I told you? All the time, they kick me to the GP. GP to refer, it takes time. (Sushila: 684-694)

### **More advice about practical strategies**

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Doctors mainly - after listening to it, we need a bit of advice from them. That's what we expect sometimes, that okay, when you come in, you talk to them. But then, er, we need a bit of like advice as well, like what you should be doing then, to come out from this problem, and how to cope with this, you know. Just to give a bit of an idea at least to, you know, to help us understand, and to put it across, to put it towards it. That would help, I think so. That part I felt a bit, uh, weak, that they didn't advise. (Amna: 965-971)

But it would be more, I think, beneficial, if they do a little bit of advice. And even, you know that when you're going to the doctors it's worth it. "I went to doctor, the doctor has advised me this today." You know, it would be better. I might be wrong, but it's just a patient or as a person would think like that... Like anything that, you know, "Okay, you have problem with such and such person in your family. Okay, try and do this, try and do that or something. Or try and talk to her..." Or any advice, you know, anything, like just as friends, how we talk. I'm not saying that a doctor and a patient can talk like friends, of course not, they don't have so much time to talk that much. (Amna: 991-1000)

### **More peer support groups**

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I would love to go to something like that, but I haven't seen, I haven't found anything, it's very very difficult. I would love to see how people are managing, because my life, I've seen like, you know, upside down everything. (Nafisa: 72-74)

There should be something going on in your own community, you know? That's something that should be there. Obviously like, every school I think they're doing, you have to go to the classes isn't it? It should be every school provides at least twice a month, they should have people like us going... You know, talk to us. Even the nurse or anybody could give us one hour time and just explain, this is how it is. It doesn't have to be subject about fibromyalgia. There is all ladies passing through, like a lot of people, and they're finding it very, very difficult. Because at the moment I'm finding very difficult phoning the doctor, because there's no answer. (Nafisa: 952-965)

## Appendix R – Author Guidelines, Ethnicity & Health



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### About the Journal

Ethnicity & Health is an international academic journal designed to meet the world-wide interest in the health of ethnic groups. It embraces original papers from the full range of disciplines concerned with investigating the relationship between 'ethnicity' and 'health' (including medicine and nursing, public health, epidemiology, social sciences, population sciences, and statistics). The journal also covers issues of culture, religion, gender, class, migration, lifestyle and racism, in so far as they relate to health and its anthropological and social aspects.

The journal aims to:

- Deal with practice and policy in a thoughtful and critical way.
- Present empirical material in a way that considers theoretical issues in addition to implications for policy and practice, given the contested nature of both 'ethnicity' and 'health'.
- Address the methodological problems that face both qualitative and quantitative studies in multi-cultural societies.

### Preparing Your Paper

#### *Structure*

Your paper should be compiled in the following order: title page; abstract; keywords; main text introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list).

#### *Word Limits*

Please include a word count for your paper.

A Research/Empirical article for this journal should be no more than 7,000 words, which includes the title page, abstract and text.

A Brief Report for this journal should be no more than 3,000 words, which includes title page, abstract and text.

A Review Article for this journal should be no more than 5,000 words, which includes title page, abstract and text.

### *Style Guidelines*

Please refer to these quick style guidelines when preparing your paper, rather than any published articles or a sample copy.

Any spelling style is acceptable so long as it is consistent within the manuscript.

Please use single quotation marks, except where 'a quotation is "within" a quotation'. Please note that long quotations should be indented without quotation marks.

### *Formatting and Templates*

Papers may be submitted in Word or LaTeX formats. Figures should be saved separately from the text. To assist you in preparing your paper, we provide formatting template(s).

Word templates are available for this journal. Please save the template to your hard drive, ready for use.

A LaTeX template is available for this journal. Please save the LaTeX template to your hard drive and open it, ready for use, by clicking on the icon in Windows Explorer.

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## Appendix S – Author Guidelines, Qualitative Health Research



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